A4 Autism Aspergers Advocacy Australia

Issue 9 October 2003

Editorial

Dear A4 member

This has been a busy month. A small number of people volunteered to help produce A4 Updates. I am especially grateful to Jo Heard and Nicole Seipel for accepting the challenge. This is their first A4 Update and I am extremely pleased with their efforts. If you agree, please let them know.

Right now just two members produce the A4 Updates. Can you give a little of your time to tell A4 about your state? We would like someone from each state/territory sending a short note for each A4 Update. And we need people who can add to the website. We've had quite a bit of positive feedback, with your help it could be even better. Can you write one or two pages (maximum) on a topic related to ASD? If so, please email me to let me know you are interested.

Previously, A4 wrote to the Health Minister. A4 received a letter from Mr Dermot Casey, Assistant Secretary, responding on behalf of the Health Minister. Mr Casey ignored the key questions asked in the letter so we wrote to the Minister again asking the same questions … and providing further detailed analysis of the additional data Mr Casey provided.

Last month we wrote to Premier Bob Carr in NSW before the last A4 Update, calling for an Inquiry into services for children with autism. As yet, Mr Carr has not acknowledged our letter. In the meantime, Learning to Learn and a large number of individuals have also written to Mr Carr about an Inquiry. Thanks to Learning to Learn for pushing this. And thanks to all those who wrote to the Premier and other NSW state politicians on this issue.

Karen Mackie, an A4 member, is shortlisted for the new National Disability Advisory Council. Karen has a range of experience as a carer. Well done Karen and good luck with the final selection. We need ASD representatives on national bodies if we are going to make a difference for people with ASD.

Dee Brough in Queensland is working hard towards national fund-raising for ASD. This is a complex issue and will likely involve state groups as much as national groups. Hopefully we will have something more definite to report in the near future.

A4's steering committee is concerned that government is just ignoring ASD. We need government to be aware of our concerns and issues. We've met with and talked to several federal politicians asking them to be aware and active. We asked them to put Questions on Notice about autism as an act of support. Two more politicians have done so (see inside).

Answers to the questions Senator Lyn Allison asked in September (see Update No. 8) are now due. In the meantime the government has changed Health Minister, now Tony Abbott MP, and the previous Health Minister, Senator Kay Paterson, is now responsible for the disability sector.

Regards

Bob Buckley (A4 Convenor) convenor@a4.org.au

Editors Notes

A4 recently received donation cheque for $500 from the Australian Property Institute, Albury. This donation came after Mr. Tim Fischer addressed a conference. A4 would like to thank both the Australian Property Institute and Mr. Tim Fischer.

A4 needs Volunteers

A4 Website

We currently require members to assist with the preparation of articles for placement on the A4 website. We have targeted the following topics for inclusion onto the A4 website in the near future:

1. I suspect my child has ASD - what do I do? Where do I go for help? What resources are available to me?

2. What is early intervention? How what where?

3. Education options, integration funding. How do I apply for funding? What sort of help can I get at my child's school/preschool eg speech therapy, physiotherapy.

4. Partnership with service providers.

5. Parenting skills and children with ASD.

6. How is the diagnosis made?

If you have experience in these areas or are prepared to research the subject matter we would be very grateful for your assistance.

A4 is committed to raising awareness within the community of children and adults on the Autism spectrum. We need your help to get our message out in the community and keep our members informed with the most up to date information.

If you can assist or require further information please contact Denise Perrett: neesyp@bigpond.com

A4 Update

We are also looking for volunteers to be our state correspondents from SA, WA, QLD, NSW and NT.

If you are interested please contact us at edit@A4.org.au for further information.

Questions

Question without Notice: Social Welfare: Carer Allowance 13 October, 2003

Questioner: Collins, Sen Jacinta (ALP, Victoria, Opposition)

Responder: Patterson, Sen Kay (Minister for Family and Community Services and Minister Assisting the Prime Minister for the Status of Women, LP, Victoria)

Senator JACINTA COLLINS (2.34 p.m.) —My question is to Senator Patterson as the Minister for Family and Community Services. Can the minister confirm that the government's review of carer allowance will see the government's test of eligibility for the payment—its child disability assessment tool—applied to permanently disabled children for the first time: that is, children who qualified for the payment under previous rules? Can the minister confirm that some children with conditions such as Asperger's syndrome and cerebral palsy, conditions that have not changed since they were first granted the allowance, will no longer qualify because the child disability assessment tool is tougher than the one applied to these children prior to 1998?

Senator PATTERSON —Senator Collins knows that a review is being undertaken of carer allowance for children. Senator Collins might not know that, when her party was in government, there was a situation where carer allowance was being applied for in situations where children were not, in fact, disabled. I remember very clearly, when I was secretary to the chairman of the backbench committee when we first came into government, going to an office out in Ringwood with Senator Newman and talking to a number of people on the front desk. They were people who had been working in what was then social security for 10 or so years and they indicated that they were concerned about people receiving carer allowance for children whose disabilities were not severe enough to warrant that.

One of the reasons they were getting carer allowance was, in fact, to get a health care card, particularly people with asthma. So Senator Newman worked with Dr Wooldridge to ensure that people with children with asthma could get a health care card without needing carer allowance. There were situations where people were getting carer allowance when the child did not have a disability that warranted it or when the child's disability changed over time and they learned to deal with the disability. These situations do not require carer allowance and it is only appropriate that they should be reviewed from time to time.

As Senator Vanstone has said earlier, when they were undertaking these reviews there were some disabilities where it was quite obvious that the disability did not change significantly and those conditions were added to the list of those that would automatically receive carer allowance and not require a review. It is important that we review allowances from time to time. Because children's situations change as they grow and develop and learn to cope with their disability, there will be situations in which a parent may have been eligible for a carer allowance earlier on but not necessarily later on as the child develops. So it is appropriate that they be reviewed. It is being done in a way that ensures that people who deserve and require a carer pension continue to receive one.

Senator JACINTA COLLINS —Mr President, I ask a supplementary question. Of course, none of that justifies the now tougher review test that is being applied. Is the minister aware that Senator Vanstone promised that children with any of the six disabilities she has listed as automatic qualifiers for carer allowance would not be reviewed prior to their 16th birthdays? Is the minister also aware that the list of automatic qualifiers is reviewed every two years? Can the minister who was dumped confirm that in fact families with children with one of the six newly listed disabilities may lose the payment in two years time contrary to Senator Vanstone's promise?

Senator PATTERSON —I believe the number of children who were reviewed and deemed to be still eligible would indicate that it is highly likely that those conditions will remain on. It is very typical of Senator Collins to run a Labor scare campaign. That is what you are going to do. Also, Senator Collins, I would suggest that you have some guts and do not actually read out every single word in the question that has been given to you. Some other people are prepared not to do that.

Questions on Notice in the House of Representatives 16 October 2003

Ms Gillard MP is the Shadow Minister for Health. The Health Minister is Tony Abbot MP.
2657 MS GILLARD: To ask the Minister for Health and Ageing -

(1) How many people in Australia were, and what proportion per 100,000 of population was, diagnosed each year for the last ten years with (a) Autism, (b) Asperger's Syndrome, and (c) Pervasive developmental disorders or autism spectrum disorders and related disorders.

(2) What are the comparable international rates of diagnosis (either an international average or figures for comparable nations).

(3) Is the Government aware of (a) the availability of diagnostic services for autism and related disorders in each State and Territory, and (b) any waiting lists for diagnostic services; if so, how long are the waiting lists.

(4) Does the Government have any evidence indicating that Australian children are being diagnosed incorrectly with autism; if so, (a) to what extent, and (b) by whom.

(5) Does the Government have any evidence indicating that Australian children are being diagnosed incorrectly with Asperger's syndrome; if so, (a) to what extent, and (b) by whom.

(6) Is he aware of the value of intensive behavioural programs in reducing the requirements of children with autism for special education and other costly interventions (Medical Journal of Australia 2003; 178 (9): 424-425) and does the Government provide any policy, coordinating or monitoring role in relation to these services.

(7) In respect of these programs in each State and Territory, does the Government collect any information on the (a) availability in each State and Territory, (b) funding, (c) level of intensity, (d) evidence of effectiveness, (e) specialist supervision by State and Territory governments of service delivery, (f) number and proportion of children with autism accessing an intensive behavioural program, and (g) parental involvement; if so, can this information be provided for the most recent year available.

(8) Does the Government have any information on comparative health outcomes for Australians with developmental disabilities; if so, can this information be provided for the most recent year available.

(9) Does the Government have any specific plans to further investigate, review or improve the health outcomes of Australians with intellectual and developmental disabilities; if so, what are the details.

The Notice Paper for the Senate, has the following Questions on Notice: *8 October 2003*

2186 Senator Lundy: To ask the Minister representing the Minister for Health and Ageing—

(1) At what rate are Australian children currently being formally diagnosed with an autistic disorder.

(2) At what rate are Australian children currently being diagnosed with Asperger's Syndrome.

(3) Are the rates of diagnosis higher than was previously observed for:
a) an autistic disorder;
b) Asperger's Syndrome; and
c) pervasive developmental disorders/Autism spectrum disorders (ASD).

(4) Is Professor Fiona Stanley, Australian of the Year and a senior epidemiologist, correct about the existence of an epidemic of autism; if so:
a) what is the extent of the epidemic;
b) is the Government concerned about this epidemic; and
c) what action is the Government taking in relation to the increasing numbers of ASD diagnoses among Australian children.

(5) Given that information from authoritative sources in the United States, that outcomes for children with (untreated) Autism are especially poor; and the findings of the Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition, Text Revision (DSM-IV-TR) that: 'Available follow-up studies suggest that only a small percentage of individuals with the disorder go on as adults to live and work independently. In about one-third of cases, some degree of partial independence is possible. The highest functioning adults with Autistic Disorder typically continue to exhibit problems in social interaction and communication along with markedly restricted interests and activities.'(p.73); and given that the United States Senate reported that 'Three quarters of those with autism spend their adult lives in institutions or group homes, and usually enter institutions by the age of 13'; does a similar situation exist in Australia.

(6) What proportion of Australian adults with autism live independently.

(7) What proportion of Australians with autism work independently.

(8) How many, or what proportion of, Australian children aged 13 years or older with autism spend on average one or more nights per week in care or away from their family home: (a) is the level of unmet need for this type of service measured and reported; if so, how is it measured; and (b) what is the observed level of unmet need.

(9) What other long-term outcomes are observed or reported for Australians with Autism.

(10) What specific treatment do Australians with autism receive for their disorder.

The Questions on Notice in the House of Representatives currently contains: *8 October 2003*

2559 MS ELLIS: To ask the Minister for Health and Ageing—

(1) What data is available on the number of children in Australia on waiting lists for an autism/autism spectrum disorders (ASD) assessment.

(2) What data is available on the waiting times for children to have autism/ASD assessment.

(3) In respect of Table 5.6 on page 70 of the Australian Institute of Health and Welfare (AIHW) report *The burden of disease and injury in Australia*, what data was used to estimate that autism represents Australia's fourth highest burden of disease and injury for boys aged 0 to 14 years.

(4) Is the AIHW planning to review health outcomes for people with developmental delay; if so, when will the result of this review be available.

(5) How much (a) in total, and (b) as a proportion of the National Health & Medical Research Council funding will be spent on research specifically related to autism/ASD in (i) 2003, and (ii) 2004.

(6) How much (a) in total, and (b) as a proportion of the Australian Research Council funding will be spent on research specifically related to autism/ASD in (i) 2003, and (ii) 2004.

(7) Will he identify any other funding programs or projects being conducted specifically in respect of the treatment for autism/ASD in Australia.

(8) Does the Government direct or intend to direct any funding specifically to autism/ASD research in Australia.

(9) How does the proportion of Government research funding spent on autism/ASD compare to the relative burden autism/ASD imposes on the Australian community.

(10) Is the Government aware of any data on the financial cost to Government when people with autism are not treated appropriately.

(11) What data is available on the long-term cost-benefit resulting from evidence-based treatment of children with autism (eg. as a result of the reduced need for intensive services when the child becomes an adult).

(12) What data is available on the direct cost to Government of caring for Australians with a diagnosis of autism/ASD.

23 October 2003

2663 MR BYRNE: To ask the Minister for Health and Ageing—

(1) Does the Government accept the classification of Pervasive Developmental Disorders (PDD), including autism, as clinical conditions by the American Psychiatry Association, in the 4th edition of the *Diagnostic and Statistical Manual of Mental Disorders* published in 1994; if not, why not.

(2) If this classification is accepted, (a) how have services for people with autism changed to reflect the clinical nature of autism, and (b) what clinical attention and intervention is provided for people with these conditions by the Australian health system.

(3) Does the Government have any information on the unmet demand for the clinical treatment of autism; if so, what.

(4) In respect of the finding reported at the first World Autism Congress held in Melbourne last year that a significant number of mental health patients in Australia who do not respond to treatment for schizophrenia were found to have undiagnosed autism spectrum disorders, (a) what is the Government doing to improve the detection of autism spectrum disorders in mental health patients, and (b) will the Government act to ensure that the treatment provided for people with multiple diagnoses that include autism spectrum disorders is effective for their combination of conditions.

State/Territory News: New South Wales

Elle should count her blessings *Sydney Morning Herald (October 9, 2003)*

If Elle Macpherson is so stressed out from the rigours of being a multimillionaire working mother that she has checked herself into a $10,000-a-week private clinic, what hope is there for the rest of us?

"Elle's stress hell" is the *New Idea* coverline this week: "It all came crashing down at a dinner in the Bahamas which Elle was organising for 75 people."

Newspapers and magazines all over the world have been speculating about what is "tormenting" the supermodel mother-of-two (who is either 40 or 39, depending on whether she was born in 1963 or 1964; she has cited both).

One report says Elle is exhausted from juggling her lingerie empire commitments with being a mother to Cy, eight months, and five-year-old Flynn. Another has her under "ridiculous" pressure to lose weight since Cy's birth. Yet another has her hitting the wall after a summer of hard partying with Jade Jagger.

Grainy pictures show a glum-faced Elle greeting her glum-faced fiance, Arkie Busson, outside The Meadows clinic in Arizona. There are also photos of her parents, who divorced when she was a child but have reunited and flown halfway across the world to help.

After six weeks of intensive counselling and family therapy at The Meadows, *New Idea* claims: "Patients hold hands as a drum is beaten and a Native American Navaho medicine man waves a feather to mark letting go of emotional baggage".

But if Elle thinks her life is so dire, rather than wasting money on new-age mumbo jumbo, she might like to try an old-fashioned reality check. Just for one day step into the shoes of a mother with real problems.

Take Elizabeth Sheedy, of Artarmon, for instance. At 40, she's the same age as Elle, who grew up in Killara, a few kilometres from the Sheedy home. Like Elle, Sheedy has two children, the elder also a boy of five.

But Sheedy's son, Jonathan, is autistic. Merely getting through every day is a struggle. "It wears you down," Sheedy said yesterday. "Every night I flop into bed and think, 'thank God that's over'. "My life is geared around Jonathan's [therapy] or working to pay for it. I would never have a night veging out in front of the TV. [But] I couldn't live with myself if I didn't do everything I could for him."

Autism is a neurobehavioural disorder that affects up to one in 1000 Australian children, and involves problems with language, social interaction, obsessive behaviours and sensory distortion. Many autistic children will end up institutionalised unless they undergo expensive, labour-intensive treatment, for which there is little government funding. The plight of autistic families was highlighted in August when Daniela Dawes, 38, was charged with the murder of her autistic son Jason, 10, at their Kings Langley home.

Sheedy says she understands. "How is it possible that families are left to suffer in this way when our country is so wealthy?" Sheedy says she and all the mothers of autistic children she knows through her support group are depressed and on medication. "We're all in survival mode."

One of the most difficult aspects of autism is that Jonathan can be aggressive and violent, and pose a threat to his three-year-old sister.

"You can never relax, never leave him unsupervised," Sheedy says. "Most children are restrained by wanting to be liked. He doesn't particularly care about what we think of him. If we're angry with him it's water off a duck's back."

Sheedy, a finance professor with a doctorate, and her husband, earn a high enough income between them to afford the $30,000 each year they spend on Jonathan's therapy, based on a US program, developed in Wisconsin, which Sheedy swears by.

As vice-president of Learning to Learn, the 100-strong parent association that has brought the Applied Behaviour Analysis method to Sydney (learningtolearnsydney.com) Sheedy says the systematic way of teaching appropriate behaviours, especially if applied before age four, can help the child into mainstream schools. Each week the Sheedys pay students to come to their house for 21 hours and teach Jonathan to talk and socialise. So far they have had pleasing results. At age three, Jonathan's IQ was 73, below the average of 100. After a year of therapy it had risen to 96 and is now at 109. He has learned to talk and is working on making eye contact.

The most heartbreaking aspect of Jonathan's condition is his lack of social judgement. Sheedy sees the "normal" children at his mainstream kindergarten exclude him.

"Seeing him rebuffed by other children is soul-destroying ... He wants to relate to other children but he invades their personal space and his voice is quite loud and monotone so you can see kids back away from him."

So every Saturday night she and her husband make videos of themselves playing children's games and dressing up as pirates so Jonathan can see how children are supposed to relate.

Next year he will start at a regular public school and Sheedy says: "I now feel confident he will have a normal education and employment." But she is concerned such intensive help isn't available to less-affluent families because of the cost of hiring carers. Of the $30,000 cost of therapy, the Federal Government provides $5000. This will come under review next year. While the therapy is expensive, Sheedy says cost of early intervention is much less than the cost of supporting a dysfunctional unemployable person for life.

"I find it so tragic. A lot of [autistic] kids would be getting just a few hours of intervention here and there. We're consigning those kids to a bleak future."

Sheedy's message to parents like Elle with healthy children is to count their blessings. "I

increasingly find it difficult to relate to mothers of normal children. They talk about their problems and I think, 'Oh I wish I had your problems.' "

No one would wish Elle anything other than a speedy recovery. But the more privileged you are, the more it helps to realise there are people whose problems make your own pale by comparison.

This story was found at: http://www.smh.com.au/articles/2003/10/08/1065601908790.html

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State/Territory News: Victoria

Victorian Report Released

The Department of Human Services in Victoria recently released a summary called *Autism in Victoria: An investigation of prevalence and service delivery for children aged 0-6 years.* It looks at children up to age 5 years and is a summary of a detailed report. You can download the summary from here.

Associate Professor S. G. Crewther and her colleagues compiled the full report. One of the A4 steering committee members, Cathy Ryan, was part of the research team. Contact Ms Karen Stewart at Specialist Children's Services, Department of Human Services Melbourne to receive a copy of the full report (A4 has not yet received a complete copy of the full report). A4 particularly likes the prospect of a "new approach" in Victoria involving:

- all children with ASD or probable ASD being able to receive immediate and effective early intervention; and
- parents getting immediate access to information and education.

The summary puts numbers to many autism-related issues and provides a basis for informed policy development. The information it provides mixes positive and negative aspects of the existing service climate.

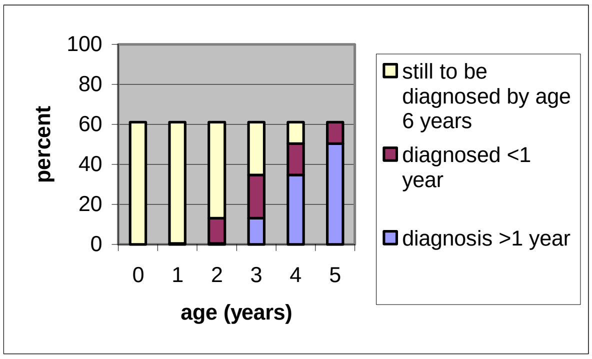
- Parents were frustrated by "the inability to access 'immediate early intervention' for their child". The report says "there is currently not sufficient funding to ensure immediate access to early intervention programs for all children with ASD".
- While most children known to service providers are receiving services, outcomes for children are less than ideal
- Half the service providers believe they offer 'best practice'. Almost half the parents feel the services their child gets are not adequate.
- 37% of service providers say 2-4 hours of intervention per week is optimal for ASD. Another 32% say 6-10 hours per week is best. A4 is not aware of credible evidence supporting the view that such low level intervention produces lasting improvements across a range of functional skills for children with autism/ASD.
- 63% of families spend $1,000 to $10,000 per annum to access the services they need and 9% spend more than $40,000 per annum.
- 34% are able to attend an early intervention service even though they do not yet have a formal diagnosis, showing diagnostic delay may be less of a barrier to service access for some than it could be.
- 94% of the carers of young children with ASD receive the Carers Allowance; but 6% aren't.

Regular reviews are a significant burden.

- “only 5% are currently considered to be either high functioning, or have Asperger’s Syndrome” showing diagnosis in young children still needs to improve significantly.

The summary says 27 per 10,000 Victorian children aged 0-6 years have a diagnosis of ASD. This estimate needs to be used very carefully. It describes the number of early intervention places required given the existing diagnosis pattern. It does not show the number of children entering school with an ASD diagnosis or the prevalence of ASD in the population.

The Western Australian Autism Registry found 50% of children are diagnosed by age 4 years (prior to their 5th birthday). This same data shows 61.18% are diagnosed by their 6th birthday. Figure 1 below shows children who have yet to reach their 6th birthday divided into three groups: those diagnosed at a younger age, those diagnosed at their current age and those who are not yet diagnosed but who will be diagnosed by age six years. At any point in time, only 43.6% of the children who will be diagnosed with ASD by their 6th birthday will already have a diagnosis. If Victoria has a similar pattern of diagnosis, around 62 children in each 10,000 children will have an ASD diagnosis when they first go to school. The diagnosis rate will increase further by the time they leave school.



Thus the figure given in the report is a small fraction of the people with ASD. ASD is a life-long condition that is present by age 3 years. Many people have ASD but have yet to be diagnosed. The prevalence of autism/ASD in the population or even among school children is likely to be far higher than the diagnosis level reported in this summary.

The full report shows high variability of diagnosis rates between the three regions on which the prevalence estimate is based. The Loddon Mallee region was lowest, Northern region in the middle and Western region highest with peak diagnosis rates of 73 per 10,000 in children aged 3 years and 66 per 10,000 in children aged 4 years. The diagnosis rates for children aged 5 years were consistently and significantly below children aged 3 years and 4 years; which is a feature of the data deserving review. Diagnosis rates may be significantly higher in Victoria than this summary shows.

A4 is concerned that programs for young children might “focus on what the child is doing, not what the child is not doing”. Parents do not want a program for their child that focuses mainly on Thomas the Tank Engine and faecal sculpture. Instead we expect a program that develops verbal skills when a child is non-verbal, social skills when a child is asocial and so on. We want children with ASD taught essential functional skills that they lack.

The summary provides information that could help improve services and outcomes for children with ASD and their families. We hope the Victorian government will use the summary and the full report to develop services and measures that clearly show significantly improved outcomes for people with ASD. We are concerned that the government released the summary but has not described how it will approach the numerous issues raised in these reports.

Where are our autism champions? Report on the outcomes of the Wangaratta Summit on Autism Services

This was the question put to Liberal Members of Parliament Victor Perton, Wendy Lovell and David Davis at a Community Summit in Wangaratta discussing the unmet needs of children and families affected by Autism Spectrum Disorder.

The three MPs - the Shadow Ministers for Education, Health and Women’s Affairs respectively, spent the day looking at special needs facilities in the north east of Victoria, where Wendy is the sitting Member of Parliament.

Victoria’s peak autism groups - Autism Victoria and the Autism Family Support Association - provided the speakers to lead the summit’s discussion. Amanda Golding and Dr. Lawrie Bartak from Autism Victoria and Meredith Ward of the Autism Family Support Association spoke with authority, passion and conviction about the plight of autism affected families.

The day of the summit, a rally was staged in Melbourne opposing the Bracks Government’s cuts to disability support funding. Meanwhile, across the border in NSW, a news report appeared in the papers telling the tragic story of Daniela Dawes, a mother charged with murdering her ten year old autistic son. The family “had almost no support” from anyone in government.

In a packed room at the Wangaratta Club, families and carers of the North East poured out their feelings on what was missing, what Government needed to do and how the world could become an easier place for children with autism. Their stories were notable for the striking similarities between them. Parents, teachers, welfare and health professionals and carers were united by a bond of understanding, tempered by their shared feelings of frustration, powerlessness and exhaustion.

Broadly they spoke about the:

- absence of adequate Government support and care,
- their tremendous difficulties gaining access to services and basic information,
- problems with uneven standards of professional expertise in the diagnosis and case management of autism and ASD's;
- a limited awareness in the community about ASD and a historical tendency to inaccurately and wrongly blame bad parenting for the syndrome as well as a lack of specialisation in ASD by professionals,
- lack of funding and a shortage of long term focus on outcomes and families rather than unstable shorter term funding
- autistic children were falling through gaps in the state government system.

Said one:
"The main issue is for these children to learn to become a part of society - a huge task."

Wangaratta couple, Ross and Heather Woodrow, parents of Matthew, dramatically illustrated this critical state wide issue. Ross, a veteran senior constable in the Victoria police force and Heather a mother of four energetic boys, have fought the system for more than eight years in a bid to find appropriate services for their autistic son, Matthew.

Although severely autistic, Matthew has been ineligible for assistance because of the rigidity and unrelenting inadequacy of bureaucratically determined cut off points limiting the numbers of eligible funded and assisted disabled children off from the ineligible children, who must make do in the mainstream. The difference between the two groups can be as low as a single Intelligence Quotient (IQ) point. An IQ of seventy and you're in; seventy one or more and you're out. The difference is naturally negligible.

When the MP's met Ross and Heather, the parents reported they were on the verge of splitting up their family: Ross taking a package and retiring early from the police force to bring Matthew to Melbourne as a sole parent to be educated at a special school, while Heather and their three older boys remain behind. Stories such as the Woodrows' are not uncommon. Parents with autistic children and disabled children go to great lengths to improve the quality of their children's lives. Parents in regional areas and metropolitan areas each face particular challenges. Like most parents the Woodrow's are motivated by one thing: "He's happy and every child deserves to be happy."

Report continues at: www.victorperton.com

Research

Measuring the Parental, Service And Cost Impacts Of Children With Autistic Spectrum Disorder

Jarbrink K, Fombonne E, Knapp M.

Reprinted from: The SCHAFER AUTISM Report (Sept 12, 2003,Vol. 7 No. 186)

Centre for the Economics of Mental Health, Health Service Research Department, The David Goldberg Centre, Institute of Psychiatry, De Crespigny Park, London SE5 8AF, UK.

The aim of this study was to carry out a preliminary examination of a research instrument developed specifically to collect cost information for individuals with autistic spectrum disorder.

There is very little cost information on children or adults with autism or autism-related disorder, and no study appears to have carried out a specific cost collection in this area.

Although some global cost estimates can be made, little is known about the cost implications of parental burden.

By using different techniques to collect indirect costs, the study outlines a functional methodology.

Results from this small pilot study point to considerable economic burden for parents and give some indication of the associated costs of autistic spectrum disorder.

http://www.ncbi.nlm.nih.gov/entrez/query.fcgi?cmd=Retrieve&db=PubMed&list_uids=12959418&dopt=Abstract

Sibling Relationships When A Child Has Autism: Marital Stress And Support Coping

Reprinted from: The SCHAFER AUTISM Report (Sept 12, 2003 (Vol. 7 No. 186)

Rivers JW, Stoneman Z. Autism Consultant, Portsmouth, VA, USA.

Family systems theory was employed to study sibling relationships in 50 families with a child with autism.

Typically developing siblings expressed satisfaction with their sibling relationships. Parents were somewhat less positive about the sibling relationship than were the siblings themselves.

As hypothesized, stress in the marital relationship was associated with compromised sibling relationships.

Informal social support buffered the deleterious effects of marital stress on positive, but not negative, aspects of the sibling relationship.

Contrary to predictions, families experiencing high marital stress who sought greater support from formal resources external to the family had typically developing siblings who reported a higher level of negative sibling behaviors than families who sought low levels of formal support.

Findings reinforce the importance of considering family context as a contributor to the quality of the sibling relationship.

http://www.ncbi.nlm.nih.gov/entrez/query.fcgi?cmd=Retrieve&db=PubMed&list_uids=12959417&dopt=Abstract

Awareness

Student With Autism Catches Senator's Ear [From WNEP, Pennsylvania]

Reprinted from: The SCHAFER AUTISM Report (Tues, Sept 30, 2003 Vol. 7 No. 198)

Parents of autistic children are looking forward to better understanding of and treatment for their children. One of the signs of progress was a brief but important speech given to U. S. Senator Arlen Specter by a youngster from Hazleton Area.

“My name is Joseph Gans, I'm 15-years-old,” that was what the sophomore student said to Specter thanking the lawmaker for the $1.25 million dollar grant for autism research in Luzerne county.

Joseph spoke for himself and others with the disability that centers on communication, “I wanted to tell you that without help, I would not be able to stand here to tell you about me today.”

“When Joey was 18-months old he couldn't talk. When he was 3-years-old he couldn't talk. He couldn't pay attention, he was difficult to teach, but with a lot of work a lot of effort, he's an Honor Student at Hazleton Area High School. He does well,” Joe Gans, Sr. speaks highly of his son.

“Now I have a great group of friends that I call the Fabulous 5 that help me with everything,” Joseph says from the podium at Geisinger Medical Center in Plains Township.

His mother, Pat Gans, said Joe includes himself in the Fab 5, “They go hunting. They go fishing, and they do play with him. They're also a support team in school. There's one in each class. One of his friends attends one of his classes. During the year he has a back up system, as well in the social end of it.”

The Gans find parents of children with autism often fight an uphill battle. “It's often misdiagnosed as a learning disability. The money Senator Specter brought to our area for autism research and treatment might change that.”

“Thanks for helping me and other children like me,” young Gans says in closing his speech.

Who knows, one day we might see young Joe Gans take his message to Congress himself.

http://www.wnep.com/Global/story.asp?S=1454534

We Must Do More To Help Parents Cope With Autism *by Terry Wylde*

Reprinted from: The SCHAFER AUTISM Report (**Wednesday, October 01, 2003 Vol. 7 No. 199)**

No sleeping! No sleeping! Every time I started to drift off, the hand would snatch out and peel my eyelids back. And the questioning. The interminable questioning. And the screaming. The interminable screaming. I was never allowed to sleep for more than a few hours a day. No phone calls were allowed. Just the daily grind of questions and screaming and unpredictable behaviours in a never-changing regime. This was my daily existence for 13 years. My daughter has Asperger Syndrome, a form of autism. To have a handicapped child is devastating, but to have an autistic child perhaps doubly so. There are very few physical signs anything may be wrong, it is often only strange behaviours and obsessions which can alert to the condition. You have to get used to people thinking you are a bad parent who cannot control your child, doctors calling you over-anxious, even family members dismissing your child as a spoilt brat. Friends shun you, as they cannot cope with the child’s behaviour.

It took ten years of constant fighting and research for my daughter to be diagnosed as having Asperger Syndrome. The system does not want to label your child because it does not want the expense of having to take on the responsibility of education and support.

Diagnosis is a bitter-sweet victory. On one hand, you have the validation that your child is not a badly-behaved fiend, but on the other hand, you have to grieve for your lost hopes, while getting on with the business of doing the best you possibly can. Love is never an issue, your parental instincts grow even stronger, but no amount of unconditional love will suffice, nor can you do it single-handedly - your child needs a team and the right education.

Experts agree early intervention is the key to future success. But, how easy is it to get that type of help? Almost impossible - you find yourself being blocked at every turn, stymied by so-called experts and why? Because it costs a fortune! In the six years it took to find the right school, and then fight for her chance to be admitted, I lost hope many times. Now my daughter is happily ensconced in a specialist school in Derbyshire. There are a handful of such schools in Scotland, but only one that I know of capable of dealing with Asperger children, a terrible condemnation of the Scottish system in the face of a rising tide of autism.

What is it like to be autistic? I want you to imagine taking a trip to Japan. You find yourself lost in the centre of Tokyo. You cannot speak the language or read the faces of strangers, your senses are assaulted by the noise and flashing neon signs. There is nowhere to turn to for help. Also, your skin has become super-sensitive, your clothes are chafing and irritating at every step, and your hearing has become so acute that you hear your own blood running through your veins. Ready to freak yet? My daughter is a superstar - she suffers all this and more, has no spatial awareness and difficulties with motor skills, yet she is frighteningly articulate, clever, outgoing and funny; a true example of triumph of spirit. It is said Asperger Syndrome affects only one out of 100 autistic people, that the ratios of boys to girls is 9:1 and places exist for only 28 per cent of all diagnosed autistics - this truly makes my girl a one in a million.

Her school, Alderwasley Hall School, has worked hard and successfully helped her overcome certain of her disabilities. Although she faces an uncertain future as schooling comes to an end, at least there is hope. If she had remained in the Scottish system, the possibilities would have been bleak or non-existent.

It is not easy to find appropriate schools, there is no central register and education authorities will only recommend their own autistic units. The paucity of places in the face of the growing population of autistic individuals is a matter of grave concern and with only two independent schools in Scotland - Struan House, the Scottish Society for Autism school in Alloa and Daldorch, the National Autistic Society school in Ayrshire, the situation is dire.

Advocacy

An Update On ASA's Ongoing Advocacy Activities: Labor, Health and Human Services Spending Bill Moves to Conference; Additional Funding Provided for Autism

Reprinted from: *ASA-Net* (The Autism Society of America's e-Newsletter) ***September 30, 2003***

This past spring, the Autism Society of America asked our members to contact their federal representatives regarding funding for autism research and surveillance at the Centers for Disease Control and Prevention (CDC) and the National Institutes of Health (NIH).

Thanks to your efforts, more than 90 Members of Congress signed a letter supporting these requests. Now, at the end of September, the spending bill that funds these agencies has traveled through both the House and the Senate and is awaiting a conference by the two chambers. We are pleased to report that, thanks in large part to your efforts, both the House and the Senate provided for increased funding for autism over last year's level at the CDC's National Center for Birth Defects and Developmental Disabilities (NCBDDD). Prior to final passage of the bill, both chamters wil meet to work out all discrepancies in the bills. On behalf of the autism community, the Congressional Autism Caucus (CARE) co-chairs, Representatives Chris Smith and Mike Doyle, have weighted in with the leadership in support of the House figure (an increased of $2.5 million versus the $1.5 million in the Senate).

Leading up to the Columbus Day holiday, most Members of Congress will return to their district for several days. This is a great time for you to meet with your federal representatives or to attend a town hall meeting. As Congress works to pass the spending bills, and the Senate considers taking up the reauthorization of the Individuals with Disabilities Education Act (IDEA), your input is critical!

The ASA encourages you to speak with your Members of Congres during while they're in town during this time. For more information on how to schedule a meeting or what to request, please click here, or go to the ASA Web site and click on "Advocacy."

The Art of Patient Advocacy By Christine Haran

Reprinted from: The SCHAFER AUTISM Report (**Thursday, Sept 18, 2003 Vol. 7 No. 190)**

Today, many people living with chronic disease are not just patients, but also highly informed and passionate patient advocates.

While some get involved locally, by leading support groups or organizing fund-raising drives, others lobby for federal health care legislation. Although it helps when there is a celebrity behind a cause, there are many lesser-known advocates who work tirelessly on behalf of people living with serious illness.

Patient advocates can be a powerful force when they descend on Washington to convince legislators to keep an eye on a cure, and assure patient rights and insurance protection.

With last year's introduction of the Inflammatory Disease Act, the Crohn's and Colitis Foundation of America, or CCFA, has been leading an effort to pass legislation that will increase funding for research and improve insurance benefits for people living with inflammatory bowel disease.

Below, Suzanne Rosenthal, who founded the CCFA shortly after her own inflammatory bowel disease diagnosis, discusses the role of patient advocates, and how people can get involved in advocacy efforts.

What is the CCFA? The Crohn's and Colitis Foundation was founded in 1967 to find the cause and cure for Crohn's disease and ulcerative colitis, which collectively are referred to as inflammatory bowel disease. These are chronic diseases that affect upwards of a million people, many of them children and adolescents.

What are the CCFA's goals? The advocacy that the Crohn's and Colitis Foundation is engaged in is primarily directed at passing federal legislation. Our major effort is the first inflammatory bowel disease act, which was introduced into the U.S. Congress last year. The passage of this bill in the House and Senate would add significant new dollars to the National Institutes of Health [NIH] to support inflammatory bowel disease research. We also have public education programs, patient education programs and about 380 support groups around the United States, and we have a very instructive and helpful Web site.

Why is the patient advocacy important? There are two major things that come out of patient advocacy. One is that it can move Congress in such a way that they respond by including powerful language in House and Senate bills on health issues that indicates their interest in having research advanced in the various federal institutions, such as the NIH and the Centers for Disease Control [CDC]. Secondarily, it gives people who have the disease a sense that they're doing something about it. In addition to running local advocacy chapters and running the education meetings, people feel like there's something bigger than them in which they can take part.

How can people become involved in advocacy? Getting involved with an advocacy organization is a good start. On our Web site, we have announcements about our advocacy efforts, and describe how our members and their friends and families and business associates can write letters to their congresspeople asking them to support the two bills that we've introduced.

We've waged a very significant advocacy effort on behalf of the bill, including one day two months ago, when we had 300 people come to Washington, to visit with their congressmen and senators and to learn more about what they could do when they get back home. A mother with her 8-year-old son, who has had inflammatory bowel disease since he was 2, participated. He testified before Congress, describing the illness and what it's done to him. He was brilliant.

Patient advocates can also sit on advisory panels and public education clearinghouses run by the federal government. I was an advocate representative on the advisory board at the National Institutes of Diabetes, Digestive, and Kidney Diseases, which is the major institute with the responsibility for advancing research in inflammatory bowel disease. I also served on the advisory board for the National Digestive Disease Information Clearinghouse.

Patient representatives are there to be sure that the doctors and scientists remember the patient concerns. For example, we have another perspective about how to make clinical trials more patient-friendly. We put a face on the disease. It is important for researchers to remember that these aren't just numbers on a page.

What does the Inflammatory Bowel Disease Act call for? It calls for advances in inflammatory bowel disease research at the NIH and at the CDC, as well as having the General Accounting Office look at the problems people encounter when applying for state disability insurance. It has been very difficult for a patient with inflammatory bowel disease to receive disability. The legislation also calls for other things that relate to living with the diseases such as insurance coverage for nutritional needs.

What other legislation has CCFA been involved in? We have always supported bills that affect people with chronic disease such as the Genetic Information Nondiscrimination Act, which is important in terms of protecting the privacy of the patient. We've also represented patients in terms of legislation for better access to specialty care, because these diseases are very complex in nature and are best managed by specialists who see a lot of people with these diseases.

What's the difference between an advocate and a lobbyist? An advocate is just a more palatable word for lay people and volunteers to use, because the word “lobbyist” is used now with reference to professional lobbyists, someone who is paid to represent a particular cause. But the fact is we are lobbying our congressmen, meaning informing them, educating them, which is perfectly legal.

Do you find that advocates for different diseases are able to work together or do you feel like you end up competing for funding? Overall, one could say that there's a competition for funds. But people are beginning to understand that if the water level rises, all boats rise with it. So in helping to get more money into the congressional budget for the national institutes, more funding trickles down to each disease. There's a significant bill right now … to increase funding research at the NIH, at the same time they're trying to fight wars and do everything else. So we've been advocating for that, knowing that if it helps everyone, it helps us out as well.

What is your advice to someone who wants to become a patient advocate? To learn as much as possible about the particular bill or program that's being advanced by the major advocacy organizations. And to let the people who are organizing the activity know how you'd like to get involved, whether you would want to come into Washington or whether you want to send letters to congressmen and women, as well as to visit their local offices.

Also, advocacy organization membership is very important. The Crohn's and Colitis Foundation currently has about 100,000 members. We see that as a good start, but if there are 1 million people out there who have these diseases, the percentage is too small. When we talk to our congressmen and women, it really adds impact to our message to say that there are X number of people affected, and we have X number of members who care enough about what happens in their lives to become a member, to be kept informed, and to be available to help with advocacy. The number of people involved, both directly and indirectly, is going to add immeasurably to the impact.

http://abcnews.go.com/sections/living/Healthology/HO_patientadvocacy.html

Articles

Autism; Autism rates drop in Denmark after removal of thimerosal from vaccines

Mental Health Weekly Digest (27 October 2003) Copyright 2003 Mental Health Weekly Digest via NewsRx.com

2003 OCT 27 - (NewsRx.com & NewsRx.net) -- A newly released analysis of autism registry data from Denmark by Safe Minds, a non-profit autism organization, shows that the rate of autism declined from an incidence of 1 in 500 prior to 1992, to 1 in 1,500 today, with the decline following the removal of thimerosal from infant vaccines in that country in 1992.

The analysis also uncovered a flaw in the methodology of Danish investigators published in the October issue of the Journal of the American Medical Association (JAMA) who utilized the same Danish registry data and concluded that autism rates in Denmark rose after thimerosal removal from vaccines.

"In our review of the Danish data we identified a flaw which resulted in a substantial loss of autism case records from the registry which essentially renders the findings from the JAMA study by Hviid and colleagues invalid," said Sallie Bernard, executive director of Safe Minds.

"The registry allows 10% to 25% of diagnosed autism cases to be lost from its records each year. The effect of this loss is such that the records will disappear from older age groups to a much greater degree than from younger age groups in any given registry year."

The Hviid findings are based on finding fewer older children in their 2000 registry cohort than younger ones. Since the older children received thimerosal vaccines and the younger ones did not, Hviid falsely concluded that thimerosal is not a factor in autism.

The Safe Minds analysis shows instead that the decline is likely due to the loss of records of older children from the registry records, rather than a true decline in autism rates in the older group.

Safe Minds reanalyzed the Denmark registry data and used an alternative method to avoid the record removal bias. The analysis looked at same-age children - 5 to 9 year olds - but from in 1992, when all of the children received thimerosal-containing vaccines, and 2002, when none of the children received vaccines with thimerosal.

After adjusting for the lack of outpatient records in the 1992 registry, the analysis found a 2.3 higher number of autism cases among the 1992 thimerosal-exposed group relative to the 2002 non-exposed group.

The analysis then determined an autism incidence rate for the non-thimerosal group of 1 in 1,500, while the thimerosal-exposed group had an incidence of 1 in 500, a 3-fold increase.

The higher figure is comparable to the 1 in 500 incidence level for core autism recently found in England and the 1 in 250 incidence level recently calculated for the U.S.

The thimerosal exposure level and timing in pre-1992 Denmark was comparable with that in England, while that for the U.S. was somewhat more aggressive.

"In the Hviid study in JAMA we can clearly see how the data was misinterpreted so a conclusion could be drawn to clear thimerosal from any role in autism," said Lyn Redwood, president of Safe Minds.

"This misinterpretation is not surprising given the authors' employment with the manufacturer and promoter of vaccines in Denmark, Statens Serum Institut. This conflict of interest should have been stated by JAMA."

Safe Minds is calling for a complete analysis of the Denmark autism registry data set by independent, unbiased epidemiologists who have no involvement in vaccine development, production, promotion, or administration.

This article was prepared by Mental Health Weekly Digest editors from staff and other reports.

Hon. Larry Anthony, MP (Minister for Children and Youth Affairs)

Australia's Children THE CASE FOR A NATIONAL AGENDA FOR EARLY CHILDHOOD

The Federal Government's commitment to children and their early development has been confirmed with the first step being taken towards a National Agenda for Early Childhood announced today by Minister for Children and Youth Affairs, Larry Anthony.

"The National Agenda for Early Childhood will focus on early child and maternal health, early learning and care and supporting child-friendly communities.

"The National Agenda will provide directions for a whole of Government approach for future investment in early childhood. I will be working closely with Senator Kay Patterson, Minister for Health and Ageing, Dr Brendan Nelson, Minister for Education, Science and Training, Senator Chris Ellison, Minister for Justice and Customs and Philip Ruddock, Minister for Immigration and Indigenous Affairs to better coordinate Federal Government investment.

"The Government will now develop a framework for the National Agenda which will identify objectives and priorities within the key areas. The framework will also articulate the roles and responsibilities of Governments and non-Government stakeholders. The Government will consult widely on the framework next year.

"Current approaches to investment in the early years by all Governments is ad hoc at best. There are significant gaps and overlaps in service provision and we don't link or coordinate as well as we should.

"State and Territory Governments have an important role to play and the Federal Government will ensure they have the opportunity to contribute to the National Agenda.

"There is compelling evidence on the importance of investing in the early years of a child's life. The links between what happens to children when they are young and their future wellbeing are undeniable.

"Early childhood development and experiences affect educational outcomes, career prospects, health outcomes, avoiding reliance on welfare, substance misuse, and becoming entangled in the criminal justice system.

"These outcomes are significant to all individuals, their families and communities. If we can give our children a better start, we all stand to benefit.

“Announcing the development of a National Agenda for Early Childhood confirms the Coalition Government's commitment to Australia's future. I look forward to consulting with stakeholders in the new year," Mr Anthony said.

For further information or feedback on this site email us at minister.anthony@facs.gov.au

Events Calendar

Biennial Australian Autism Spectrum Disorder Conference

Autism Association ACT & Autism Council of Australia

Friday, 1 Oct - Sunday, 3 Oct, 2004
Rydges Lakeside Canberra

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

Keynote Speakers

Dr Jeanie McAfee
[author: Navigating the Social World; see Dr McAfee's internet site here.]

Dr Tony Attwood
[well known author, trainer, presenter and diagnostician; see Dr Attwood's internet site here.]

Expressions of interest are invited for the Biennial Australian Autism Spectrum Disorder Conference
If you would like to attend the workshops or the conference or both, please e-mail the conference team at Autism ACT and let us know. We will put you on the mail list.

CALL FOR PAPERS
Currently we are seeking:

- **Papers or presentations - session duration 45 minutes - 60 minutes including a Q/A period;**
- **Poster presentations - space will be provided to display your presentation and time scheduled so you can meet people to discuss your presentation.**

If you wish to offer a paper, a presentation or a poster presentation, please contact the conference team at Autism ACT and indicate your interest, and if available, a subject/title.

You are urged to book early. Contact Autism ACT

Website Launch

www.autismhelp.info

A new website project has been launched to help foster better understanding of the needs of children and adults with autism.

The increased number of children being diagnosed with high functioning autism and a lack of awareness of the condition are the driving forces behind it's development.

Gateways Support Services in Geelong received funding from the Department of Human Services for the purpose of developing this unique project, with the aim of improving understanding and support of those children in mainstream services.

The website is nearing completion and will assist in educating parents and professionals about autism. The site also provides practical strategies for childcare workers, integration aides, preschool, primary and secondary teachers.

The strategies cover language impairment, behavioural difficulties, social interaction and more. There is also an online discussion group where information may be exchanged.

Gateways' Project Officer says 'We need to help teachers recognise the individual needs of students with autism. If teachers understand how this disability impacts on learning, these children have the best possible opportunity for success at school. This site will make it so much easier to understand the needs of children with high functioning autism and support their inclusion in mainstream classrooms.'

This website should prove to be an informative resource tool, particularly for educators and schools.

Sister Organisation

PACE is a 'sister' organisation for A4 in the UK. You can find out more information about **PACE** on the website mentioned below in the near future.

PACE has moved offices. Please note our new address and phone number:

PACE
P O Box 46551
London N1 2XT

Telephone: 020 7583 9032
Email: info@pace-uk.org
Website: www.pace-uk.org

Contact Details

Goulborn Valley (GV) Autism Spectrum Support Group
Coordinators: Jenny Tucknott and Sue Watt
Postal Address: 79 Colliver Rd, Shepparton 3630
Email: graemenjenny@iinet.net.au
PH: (03) 58 316783

A4 Convenor
Bob Buckley
convenor@a4.org.au

A4 Update Editors
edit@A4.org.au

October Profile

1. Name

Bob Buckley

2. Born

Sydney, 1950

3. Lives

Canberra

4. Family

Spouse: Dorothy; children: Kieran (12), Rhiannon (9) … Dorothy's parents: Phil and Louise; and a very close network of wonderful friends/carers.

5. Why did you become in involved with A4?

Out of frustration with ACA: I could not see it doing much beyond administering the Apex Trust Fund. I felt we needed a national organisation to complement ACA that directly represented people with ASD and their families/carers. No one was approaching federal government or agencies. The ASD community faces some challenges that need to be addressed at the national rather than state level, perhaps even at the international level. The ACA was not moving in a timeframe that would benefit my son and the rapidly increasing group of people with ASD.

A small group of us met and found we had similar views on how best to proceed so we decided to launch a national body and see if we could make it work. I believed I could contribute through providing policy ideas, analysis of relevant information and helping run the organisation and develop policy.

6. What other autism related organisations are you involved with?

- founding member (1998) and current President of Action for Autism Inc. (*AfA*)
- committee member since 1997 and sometimes member of the executive of the ACT Autism Association.
- member of Learning to Learn (when I remember my subscription)
- an ACT representative on ACA (for a short time)
- a member of the ACT Department of Education Autism Working Party (1997–98) and The ASD Advisory and Consultative Committee (TASDACC)
- Autism Behavioural Intervention Coalition (peak group for Aussie ABA)
- member of the ACT's Disability Reform Legislation Working Group

7. What do you hope to see in the near future as a result of A4?

Implementation of a national strategy for better outcomes for Australians with ASD and their associates.

There are lots of steps along the way to this goal. At the national level, government and its agencies should:

- recognise the challenge ASD presents for the Australian community
- develop effective services for people with ASD especially in health, education, employment and disability sectors
- ensure people with ASD achieve equitable outcomes in social and economic participation
- improve training of professionals and ASD-related research in Australian universities

In the immediate future, I hope A4 can get government to appreciate the nature and scale of the challenge ASD poses for the whole community.

8. Reading

For obvious reasons I don't get much chance to read for pleasure at present: recently has been Terry Prachett and Phillip K. Dick. Otherwise I read bioinformatics research, high performance computing, legislation, industrial relations and social policy, …

9. Listening To

I don't listen to much music. I play in a couple of bands: Franklin B Paverty is a Canberra institution of 30 years standing playing bush/folk/country with forays into pub-rock and blues; Alive and Pickin' plays bluegrass and newgrass.

10. Favourite Food

Mediterranean and most asian cuisines.

11. Where would you go for your ideal weekend away?

Whistler/Blackcombe or Chamonix as long as someone else is paying. For a weekend, I'll ski anywhere; or swim, walk, camp, play music, drink fine wine and eat fine food, cycle, …

12. Where was your last holiday?

Guthega, skiing and sharing catering with a diverse group of friends (who cope well with our ASD).

Or the October long-weekend at the Uranquinty folk-festival (we did 3 gigs in three days).