



Dear A4 members

following is some of the news from around the country. A lot happened this month. Some of it has been in local media so this Update contains numerous press clippings and media releases.

In the Update, we have a couple of items where we would like you to write a letter or two. If you don't live in NSW, then we ask again that you write a simple letter or email to one or more federal politicians to thank them for their interest in autism-related matters.

If you live in NSW, please be part of the call for an inquiry in NSW. Of course, you may participate in both activities.

Our former Convenor, Judy Brewer Fischer, has a new role as Chair of the new National Family Carers Voice (NFCV). In this position she is closer to political decision making than she was as A4 Convenor. Congratulations to Judy on her appointment. We know she will do an excellent job in what is likely to be a challenging position. We are maintaining direct contact with Judy; she remains a strongly committed member of our steering committee.

Some of the recent media from NSW is reproduced below. This follows on from the tragic stories in the last Update. The story provoked a strong response from the community.

Political activity about autism has increased noticeably in Victoria. Some of the media information is reproduced below.

A few people have provided information and are sharing their experiences with the review of Carer Allowance. We are also interested to know whether people in NSW are the only ones who are significantly affected by changes to the Commonwealth's In-home Care scheme.

A4 wrote to the ABC about some of its content that contains adverse and inaccurate descriptions of people with Aspergers Syndrome.

One of our members, Andrew Lee, has volunteered to look after the A4 membership Database. Thanks Andrew, this is an enormous help.

This Update is a rushed job. We really need some assistance with preparing the A4 Updates and we need to put more information on the A4 website. If you can help with either of these please let us know: could you help with layout, prepare an occasional story or do you have a favourite topic you would like to inform others about?

regards

Bob Buckley — Convenor
convenor@a4.org.au

September 2003

National call to action: thanks for help

Several politicians are currently helping A4 obtain information from the Health Minister. Senator Gary Humphries has already obtained a small amount of useful data from the Health Minister's office (see below). This information is the basis for the letter to the Health Minister that appears in part later in this Update. Our goal is to ensure the government and the Health Department describe their current understanding of autism/ASD in Australia.

We ask that A4 members write to Senator Humphries to thank him for his help. Here is a sample letter of thanks:

Senator Gary Humphries
Parliament House
Canberra ACT 2600

Dear Senator Humphries

Subject: **Thanks for your interest in autism**

Thank you for your interest in autism and for your assistance in obtaining important information about autism from the Health Minister and government.

sincerely

your name
date

Several other politicians are helping us: they asked the Minister for more information. As an example, the Questions on Notice from Senator Lyn Allison appear later in this Update. Interest from the community will increase awareness of autism/ASD among our politicians. The politicians involved so far are:

Senator Lyn Allison

Senator Kate Lundy

The Hon. Annette Ellis MP

The Hon. Kay Hull MP

It would help our cause if A4 members wrote to one or more of these politicians (use the same address, Parliament House, as above) to thank them for their interest as well.

Call to action in NSW: A4 calls for an Inquiry

Services for children with autism/ASD and their families in NSW are not adequate. If you live in NSW and share this view please write a simple letter similar to the following asking the NSW government for an inquiry.

Your address

The Hon. Bob Carr, MP
Premier
Level 40 Governor Macquarie Tower
1 Farrer Place
Sydney NSW 2000

Email: bob.carr@www.nsw.gov.au

Dear Premier Carr

Subject: **Inquiry into services for people with autism**

Services for my child who has autism/ASD and my family are not adequate and appropriate. Please conduct a comprehensive inquiry to find out what services are required and what action is needed to improve outcomes for children with autism in NSW.

sincerely

your name

date

If you can, also write to the following politicians (and any others you want):

The Hon. Morris IEMMA, MP. Minister for Health Level 30 Governor Macquarie Tower 1 Farrer Place Sydney NSW 2000 alison.mclaren@health.minister.nsw.gov.au	The Hon. Carmel Tebbutt, MLC Minister for Disability Services Level 25 9 Castlereagh Street SYDNEY NSW 2000 DOCS@tebbutt.minister.nsw.gov.au
Mr John BROGDEN, MP. Leader of the Opposition 1725 Pittwater Road Mona Vale 2103 pittwater@parliament.nsw.gov.au	Mr Barry OFARRELL, MP. Shadow Minister for Health 772 Pacific Highway Gordon NSW 2072 barry.o'farrell@parliament.nsw.gov.au
Ms Clover MOORE, MP. Independent. 58 Oxford Street Paddington NSW 2021 clover.moore@parliament.nsw.gov.au	The Hon. Dr Arthur Chesterfield-Evans, Australian Democrats. Parliament House Macquarie Street Sydney NSW 2000 ace.mlc@parliament.nsw.gov.au

If you can, get your friends and relatives in NSW to write a suitably modified letter, please do so.

A letter to the Health Minister

Here is the start of a recent letter. If you are interested, download the whole letter from <http://www.a4.org.au/documents/KP030822.doc>

Dear Senator/Minister Paterson

Subject: **Australian children with autism**

I write to draw your attention to what may be an epidemic of autism among Australian children. I suggest this is a serious health issue and is supported by information provided recently by your office. I would like to meet with you to discuss it.

I wrote to Senator Gary Humphries on 10/7/2003 with the following questions for you as Health Minister.

Prof Fiona Stanley said on Andrew Denton's show Enough Rope (Episode 10) that there is an epidemic of autism.

I would appreciate it if you would formally ask the Health Minister the following questions.

- *At what rate are Australian children being currently diagnosed formally with Autistic Disorder?*
- *At what rate are Australian children being currently diagnosed with Asperger's Syndrome?*
- *At what rate are Australian children being currently diagnosed with Pervasive Developmental Disorders and/or Autism Spectrum Disorders?*
- *Are the rates of diagnosis for these conditions higher than was previously observed?*

If Professor Stanley is right about there being an epidemic of autism, what is the extent of the epidemic? Is the government concerned about this epidemic? What is the government doing in relation to the increasing numbers of ASD diagnoses among Australian children?

I received the following by email on the 22/8/2003.

Minister Patterson's office have responded with information provided by the Australian Institute of Health and Welfare (who received their information from the ABS). The following figures are based on a survey of those who have identified themselves as disabled.

In 1998, approximately 12,900 Australians had ASD - 11,400 of these were aged 15 or younger.

I hope this information assists you.

Michael McNeill

Adviser

Gary Humphries
Senator for the ACT

The information obtained so far by Senator Humphries' Office gives a basis for further analysis. ...

Questions on Notice

Children with Autism Spectrum Disorders

Senator Allison asks the Minister for Health & Ageing:

- 1) How many children in Australia were diagnosed formally with Autistic Disorder in each of the years 1983 to 2002, by age group and by state and territory?
- 2) How many children in Australia were diagnosed formally with Asperger's Syndrome in each of the years 1983 to 2002 by age group and by state and territory?
- 3) How many children in Australia were diagnosed formally with Pervasive Developmental Disorders and/or Autism Spectrum Disorders in each of the years 1983 to 2002 by age group and by state and territory?
- 4) Can the Minister explain the disparity in AIHW data from 1998 that shows adult rates of Autism Spectrum Disorder to be significantly lower than those for children, given that this is a life-long condition?
- 5) To what extent can the disparity be attributed to better diagnosis?
- 6) Professor Fiona Stanley said recently that there was an epidemic of autism. Does the Government agree and, if so, what is the extent of the epidemic?
- 7) The Senate Employment, Workplace Relations and Education References Committee's Dec 2002 report –Education of students with disabilities – cites the incidents of autism as 27 to 93 per population of 10,000. To what extent does the Government regard Autism Spectrum Disorder as a health problem?
- 8) What are the assumptions that underlie that fact that in ABS statistics, children with autism are grouped with those with intellectual disability?
- 9) Is the Government aware that a survey of paediatricians in Victoria in 2002 identified autism as one of the more difficult areas of practice?
- 10) What measures has the Government adopted for ensuring that children with Autism Spectrum Disorders receive effective, evidence-based treatment for their condition?
- 11) Is the Government aware that the Medical Journal of Australia editorial this year said in relation to Autism Spectrum Disorder:

The early intervention that has been subjected to the most rigorous assessment is behavioural intervention. There is now definite evidence that behavioural intervention improves cognitive, communication, adaptive and social skills in young children with autism.

Most young children with autism in Australia do not receive intensive behavioural intervention programs – partly because such programs are not recommended by many health professionals and partly because of their prohibitive cost for families.

- 12) What efforts have been made by the Commonwealth to see that:
 - a) health professionals are adequately informed in the diagnosis and treatment of children with Autism Spectrum Disorder?
 - b) affordable, evidence-based early intervention from specialist behavioural psychologists is available for all children with Autism Spectrum Disorders
 - c) all children with Autism Spectrum Disorders can readily access appropriate early intervention and treatment such as speech therapy, occupational therapy and physiotherapy?
- 13) The UK Government has set up specialist research institutes for Autism Spectrum Disorders. Has the Government considered doing so in Australia and if not, why not?
- 14) What research is currently underway and what is planned in the future looking into the cause, diagnosis and/or treatment of Autism Spectrum Disorders in Australia?

Senator Lyn Allison

2 September 2003

A4 Members: write to a politician (continued)

In previous A4 Updates, members (you) were asked to

- write a letter thanking a politician for speaking in parliament about autism.
- fill in the survey form on the website after you sent your letter.

Thanks to the members who sent letters. Credible rumour has it that the public response surprised the politicians. We have the attention of these politicians so we need to build on it. Please keep letting them know when they are doing the right thing by us. Positive reinforcement works best.

As best we can tell, far more people sent letters than completed the survey form on the website (unfortunately the website was down during a critical period). So far, 32 people completed the online form and 12 of those sent letters to all four of the politicians rather than to just the one.

In the coming months, we will try to meet with these politicians in Canberra so we can explain our concerns and issues to them and inform them about what needs to be done and what they might do about it.

MEDIA RELEASE

Senator Amanda Vanstone
Minister for Family & Community Services

95.03

26 August 2003

A New Voice For Carers

A new organisation called the National Family Carers Voice has been established to provide the Government with advice on how we can better address family carer issues.

Carers are the unsung heroes of Australian society. The effort, devotion and support that they provide cannot be praised enough.

The National Family Carers Voice will gather information about the nature, location, and circumstances of family carers and will provide the Government with advice and options for addressing the longer term needs of these important individuals.

Members of the National Family Carers Voice are carers who have personal experience and a personal commitment to providing care to children and adults with disabilities, and to those who are frail-aged. Their experience includes caring in Indigenous communities, rural and remote areas and a range of ethnic groups. Young carers will also be represented.

I am delighted to announce that Mrs Judy Brewer Fischer has agreed to be the Chairperson of the National Family Carers Voice. As a carer herself, Mrs Fischer has extensive experience working in the areas of social and community support, and will bring tremendous knowledge and commitment to the Family Carers Voice.

The full membership of the National Family Carers Voice is attached.

Over the next two years, I am confident that the National Family Carers Voice will be able to enrich our understanding of what it means to be a family carer. I look forward to receiving their advice on how we can a real difference to the lives of family carers and the people that they look after.

NATIONAL FAMILY CARERS VOICE

MEMBERSHIP

	Nominated by	State
Chair:		
Mrs Judy Brewer Fischer	Appointed by Minister	NSW
Members:		
Ms Carol Franklin	Carers Australia	WA
Mr Garry Halliday	Carers Australia (Indigenous rep)	NT
Ms Felicity Maddison, AM	National Disability Advisory Council	QLD
Ms Barbara Alexander, AO	Association for Children with a Disability	Vic
Mr Keith Wilson	Mental Health Council of Australia	WA
Ms Matilda Mravicic	National Ethnic Disability Alliance	NSW
Ms Judy Forster	The Australian Federation of Disability Organisations	QLD
Mrs Delys Sargeant, AO	Council on the Ageing	Vic
Ms Lisa Kelly	ACT Young Carers Network	ACT
Ms Mary Walsh	Australian Parent Advocacy	Qld
Ms Becky Reed	Representative of South Australia	SA
Ms Belinda Smith	Representative of Tasmania	Tas

Media Statement - 27 August 2003

Government spends more on carer consultation, but continues to cut carer allowances

[Annette Ellis](#) - Shadow Minister for Disabilities

Minister Vanstone has decided to provide funding for a second national carer organisation but is continuing to strip Carer Allowance payments from up to 30,000 parents of disabled children.

The Federal Government already funds a peak national consultative group, Carers Australia, but Minister Vanstone announced yesterday that she would fund a second group, the *National Family Carers Voice*, to advise it on ways to address family carer issues.

Carers Australia receives over \$2 million of Federal Government funding, including \$322,110 in Secretariat funding from the Department of Health and Ageing to do exactly what the new organisation is supposed to be doing.

The Carers Association of Australia Strategic Plan 2001-2003 states:

"The Carers Association of Australia is the national peak body representing and promoting the needs and interests of carers through: advocacy and leadership with government and the community." (page 2)

and

"CAA's advice, expertise and information is regularly sought by government Ministers, departments, other community organisations and the media." (page 3)

Either Carers Australia isn't doing the job it is supposed to be doing, or Minister Vanstone is just wasting taxpayers' dollars in an attempt to rehabilitate her image following her decision to strip Carer Allowance from 30,000 families.

Minister Vanstone doesn't need two advisory committees to know that her decision to continue with the stripping of Carer Allowance payments to families of children with Cerebral Palsy, Asperger's Syndrome, severe chronic asthma and ADHD is heartless.

The Prime Minister promised Alan Jones that the Carer's Allowance would not be withdrawn from people because of the review. Yet this is occurring.

Those families who have already lost the \$87.70 Allowance a fortnight, despite the Prime Minister's promise, will be keen to know how much money Senator Vanstone intends to spend duplicating the \$2 million-plus carer advisory process that is already in place.

This money should go to families, not blatant face-saving exercises.

Editorial on NATIONAL FAMILY CARERS VOICE

The Minister's appointment of Judy Brewer Fischer as Chair gives the autism/ASD community for the first time an identifiable voice advising the government about our concerns. However, Judy is not identified as a representative of or having a position associated with autism/ASD.

A4 shares with Minister Vanstone, the concern that existing groups do not represent effectively carers such as many of A4's members. Annette Ellis's point that a new advisory group should not be needed is worth noting. There are numerous organisations claiming to be peak bodies and claiming to represent a range of people with a disability. Yet these peak bodies have not sought A4's views and have not represented the views other autism/ASD organisations send to them unsolicited. There is no basis for their claims to represent our views. And we have been left without a voice for too long.

Autism/ASD needs its own representation and needs to be recognised in its own right. We should expect nothing less. ASD is distinct and people ASD affects are numerous.

Tragedy in NSW and NZ (cont.)

"Those who cannot remember the past are condemned to repeat it." George Santayana (1863-1952)

The Daily Telegraph continues to report on the tragic story from Sydney (see Update No. 7). Numerous people have spoken out about their experience with being unable to access the services they need, or having to fund completely essential health and disability services from their own income.

About five years ago, the Australian press briefly reported on a tragedy in New Zealand where a mother murdered her autistic daughter. The reasons she gave were that she was unable to support her daughter and that she could not get the services her daughter needed. She felt her community did not want her daughter. There were several articles updating this story.

Some of the material from the media appears below. A more complete collection of the stories and feedback can be downloaded from our website (the URL is <http://www.a4.org.au/documents/DawesFile.doc>).

A4 is joining with interested autism/ASD groups in NSW, Learning to Learn in Sydney and Action for Autism in the Canberra region so far, in writing to the NSW government to ask for a formal inquiry into services for children with autism and their families.

Letter to NSW Premier

Dear Premier Carr,

Subject: **Judicial Inquiry into Autism Services**

Recent descriptions of the circumstances of families of children with autism mostly in the Daily Telegraph, show people feel that services and support for autism and dyspraxia in NSW are seriously deficient. Clearly, there are major concerns in the community about the services that are provided for these children and their families.

Autism Aspergers Advocacy Australia suggests NSW needs a Judicial Inquiry into the services available for children with autism, their families and other supporters. Such an Inquiry should examine the services provided for people with autism and dyspraxia.

1. As Autistic Disorder is a clinical diagnosis requiring clinical attention, the inquiry should examine the clinical services provided for the treatment and rehabilitation of children with Autistic Disorder inline with international best practice (using evidence-based methods) and the expectations of the UN Convention on the Rights of the Child.
2. Autism is generally included as a disability for the purpose of planning services so the inquiry should investigate the planning, provision and monitoring of services for children with autism and/or dyspraxia, and whether the services provided are effective services for people with these conditions.
3. Education services are crucial for children with these conditions so an inquiry should examine whether the services provided are appropriate and effective for these conditions.
4. Government has a role in protecting the rights of people with autism and/or dyspraxia to services that equalise their participation in education, employment and the community in general so the inquiry should examine whether those rights are protected effectively in NSW.

The focus of the Inquiry should be on ensuring in the future children with autism and/or dyspraxia in NSW achieve the best possible outcome as this will reduce the burden on their families, teachers, supporters and the community as a whole.

Autism Aspergers Advocacy Australia, together with Learning to Learn (<http://www.learningtolearnsydney.com>) and Action for Autism (<http://www.users.bigpond.com/actionforautism>), call on the NSW Government to initiate a Judicial Inquiry immediately. Autism Aspergers Advocacy Australia can be contacted via e-mail at convenor@a4.org.au or through our website at www.a4.org.au.

Yours sincerely

Bob Buckley
Convenor — Autism Aspergers Advocacy Australia

5th September 2003

cc:	The Hon. Morris IEMMA, MP.	Minister for Health
	The Hon. Carmel TEBBUTT, MLC.	Minister for Community Services
	Mr John BROGDEN, MP.	Leader of the Opposition

From the Daily Telegraph

Massive pressure

By TORY MAGUIRE
13 Aug 03

THE pressures on parents of autistic children were so great nearly 85 per cent of their marriages broke down, the president of the Autism Council of Australia said yesterday.

Andrew Brien, whose own young son suffers from the condition, said parents invested so much time and energy in their autistic children other parts of their lives were greatly affected.

Autistic children are sometimes known to attack their parents, injure themselves without complaint and run off without explanation, making supervision a full-time job.

"There is no intention behind this," Mr Brien said.

"They are not nasty kids. They just don't understand the world.

"They are either trying to understand or are just exceedingly frustrated."

Mr Brien said autistic kids had to be taught every single life skill individually.

Toilet training can take years if it works at all and sometimes every single word has to be taught to children one by one.

Leaving an autistic child alone, even for just a minute, can spell disaster.

Thanks to their often high pain threshold, they sometimes won't cry out or call for their parents if they are injured.

"Their perception of danger may not be the same as other children," Mr Brien said.

Adding pressure to parents in this situation was the perception amongst some in the community that autistic children's behaviour was the fault of the parents.

Minister for Disability Services Carmel Tebbutt yesterday offered condolences to the Dawes family.

"I appreciate the enormous sorrow his family is experiencing," Ms Tebbutt said.

"Jason did receive therapy services on an ongoing basis through on of the Department of Ageing, Disability and Home Care's local School Aged Therapy Teams.

"The NSW Government is aware of the challenges face by families and carers of children with a disability and has responded with a wide range of services."

There is no established cause for autism.

The Autism Association of NSW website lists four possible factors: genetics, exposure to viral diseases and infections, physical trauma such as birth injury, and metabolic disorders.

"Poor parenting or lack of love does not cause autism," the association says.

Feedback (... a small sample)

From: Katrina

Comment: its only really a matter of time till families tear apart because of autism, the stress ,the cost to sibilings to marriages .the truth nobody wants to hear ,and families are too stuffed physically to keep fighting to be heard, there is 3 yr waiting lists for services ,limited school assistance and now healthcare card re assessments. i have autism in our family. i have 2 sets of twins ,one child from each set has autism and delays associated, affect every one else. family dynamics are crushed because of autism,when you face it 24-7 ,but we cannot allow ourselves to be victums, we have a responsibilities as human beings..a child does not deserve to die ,at the hands of its mother because he has autism. i weep for that woman .limited services, government funding play apart .parenting holds the whole responsibilty, and who has the right to play GOD with their own child? ask for help ,seek help SCREAM for help..professionals have alot to answer for when they cant deleiver their services as they often promise. but in the end .. it is murder.. ,

From: Victoria

Comment: I too have a 12 year old son with Asperger's syndrome (form of Autism) on reading this story I could not help but relate to this poor woman and her family. Help wasn't there for them before, someone please help them now & support her. Nobody could ever understand the intense amount of love she would have had for her little boy. The government needs to seriously look at this issue.

From: Leanne

Comment: I too am the mother of an Autistic child. My heart goes out to the mother who felt for that brief moment that she could cope no longer. It is only through the grace of God and the love and support of my husband that we cope as well as we do. Very few families get the help that they need to raise these special children and most will never know the family lifestyle that many people take for granted. With an increase of more than 300% in the incidence of Autism in recent years unless government addresses the needs of families then I predict that the hearts of more families will be broken in the future. Some are fortunate to have extended families who freely support them in their difficult and life long commitment. Sadly many live daily with indifference and little or no support. These families live daily with Autism and do not need criticism and ridicule. They need your compassion and understanding and most of all your help. After all with 1 in 100 affected in our community now, chances are that you or your

children may one day be directly affected by Autism.

From: Ian Jin

Comment: What can I say as a father with an autistic daughter? The mother must have been supported earlier stage. It may prevent this tragedy. I can understand her motivation. I believe that many autistic child parents feel the same motivation in some stage. Ian

Free at last: mother on murder charge wins bail

By: LISA MILLER

TUE 26 AUG 2003, Page 7

THE Sydney woman accused of the murder of her autistic son was reunited with her husband and daughter last night after a local court magistrate granted her strict conditional bail.

...

Jason's death has highlighted the often desperate plight of parents and carers of autistic children, with huge waiting lists for services and lack of understanding among the community among the obstacles they face.

Dawes allegedly told police in an interview on the day of Jason's death that she felt the family had been let down by support services in the area.

Yesterday, her husband vowed to continue to campaign for better support systems, saying he did not want his son to have died in vain.

"Since the death of Jason the counselling services made available have been unbelievable, but where were they when we needed them?" he said.

A more complete collection of the media stories and feedback can be downloaded from our website. There is a story by Judy Brewer Fischer and one about Robyn Harris in Sydney. There is quite a lot of feedback from the community.

The URL for downloading the file is www.a4.org.au/documents/DawesFile.doc

Autism and Students with a Disability in Victoria

Libs Push For Inquiry Into Autism "Crisis"

[The Chronicle, Wangaratta](#)
13 August 2003

Families are being forced to educate their autistic children at home because schools can't cope with their special needs, Liberal Party shadow ministers were told at an [autism summit in Wangaratta](#) yesterday.

Parents from Wangaratta, Benalla, Mansfield, Yarrawonga and Shepparton told how inflexible and resource deprived state government education and health services were failing their children.

Parents, educators and health professionals said those with Autism Spectrum Disorder (ASD):

- were not being adequately catered for in many mainstream schools because of insufficient resources and teachers lacking understanding/skills to cater to their special needs;
- were dropping out of school early, while others were having to be taught at home because schools couldn't cope with their behavioural difficulties;
- couldn't get into special need schools because their IQ was above 70, even though they had other intellectual disabilities; and
- were missing out on critical health services, such as speech, occupational therapy and physiotherapy, because they aren't accessible publicly due to insufficient resources or geographic isolation.

Several Wangaratta parents told how they had privately funded a professional from the USA to visit and establish a home-based early intervention education program, where their ASD children could learn to read and write.

"The idea was to give them a head start for school, which was successful, but then we

The Association for Children with a Disability (ACD) and AFSA have been active in Victoria in relation to changes to funding and services for children.

were ruled ineligible for government assistance because the children were coping," a parent told the meeting.

"We were discriminated against by the public system because we had forked out our own money and a great deal of time to help our kids."

One parent said she feared her child may commit suicide because of the stresses he endured at a public school, which didn't seem to understand his special needs.

The summit was also told that diagnosis of ASD was a problem and health professionals needed to be better educated for diagnosis and treatment.

[Liberal Shadow Minister for Education Victor Perton](#) said it was clear from the summit, and feedback elsewhere across the state, there is an endemic crisis which needs to be addressed in a bi-partisan manner.

Mr Perton, together with Shadow Minister for Health, David Davis, and Wendy Lovell (MLC North Eastern Province) said after the meeting, they would seek Labor Party and National Party support for a parliamentary inquiry.

[Autism Victoria](#) president Dr Lawrie Bartak said ASD was a very complicated thing to deal with, given the wide ranging conditions and the fact most, but not all, with ASD also had some form of intellectual disability.

He said around one per cent of the population was now suffering from some form of ASD, yet state government resources fell well short of matching this prevalence.

Wangaratta Lions Club committee member Eddie Flynn, who was at the meeting, said the club was keen to continue to do its part to help local families with autistic children, with another public meeting scheduled for September 11.

BETTER DEAL FOR STUDENT'S WITH A DISABILITY; ALLAN

The Bracks Government will improve support services to students with disabilities in Government schools, the Minister for Education Services Jacinta Allan said today.

"These changes will help establish world's best practice in Victoria, meaning better results for students in classrooms and greater flexibility for schools to deliver services," Ms Allan said.

"The services to help disabled students in schools have been largely unchanged for a decade.

"These reforms will help ensure the fairest possible system for students and address significant growth in recent years.

Key elements of the reforms for the 2004 school year were;

- Funding for categories one to six to remain at current levels;
- Recruiting additional speech pathologists;
- Reviewing the Educational Needs Questionnaire to ensure a fairer system;
- Strengthening professional development for teachers and aides to improve school based expertise;
- Piloting better assessment and monitoring mechanisms, and;
- Further improving the standard of curriculum for students.

Ms Allan said a separate program for students with language disorders would be established from 2005.

"Over the last couple of years there has been unprecedented growth, in some areas as high as 177 percent, in the diagnosis of children with language disorders, which is beyond reasonable expectation.

"We need a better educational response that doesn't brand these children and recognises that one size doesn't fit all.

"Our first priority is always the best outcome for students. "Everyone agrees these children should not be labelled "disabled" for their whole school career, when short term help to address language and speech problems is more appropriate.

Re: State Government announcements from Minister Allan's office regarding students with a disability

Michael Gourlay, the Chief Executive Officer of the Association for Children with a Disability said,

"We're relieved that common-sense has prevailed and that the government has guaranteed to maintain funding for all students with a disability in 2004.

From 2005 the dedicated program for language disorders will:

- Cut paper work for speech pathologists, allowing more time in the classroom;
- increase access to speech pathologists;
- enhance links with the Department of Human Services to provide support earlier;
- reduce demand through early intervention strategies;
- boost training of program aides, and
- enhance links with existing literacy and numeracy programs.

"We will also aim to ensure the new language disorder program complements other programs in schools, such as the English as a Second Language program and literacy and numeracy programs.

Ms Allan said funding for support services for students with a disability is at record levels.

"Payment to schools under the program has grown by 60 per cent in the last five years, from \$122.6 million in 1999 to \$197.3 million this year.

"We want to ensure that money is being spent to best meet the requirements of those students most in need of help.

The reforms would build on improvements to the program already made by the Bracks Government, including regular reviews of students on the program and the establishment of an independent advisory panel.

Many of these changes were first flagged in 2000 and have been the subject of ongoing consultation with stakeholders, including principal and parent groups, unions and groups representing students with disabilities.

New initiatives will be developed in close conjunction with those affected by change.

August 1, 2003

The Minister deserves to be congratulated for listening to parents on this issue.

"Some of the other enhancements to the Program for 2004 are also most welcome, in particular the commitment to more speech therapists in schools.

"As for the plans for 2005 and beyond in relation to children with language disorders, we'll be keeping a close eye on the government's plans to make sure they don't short change parents and schools. Kids with language disorders need additional assistance within schools and if they're not going get it as part of the Disability Program, it needs to be there from other sources.

September 4, 2003

Carers Review form

Dear A4,

I write from ABIT in Tasmania to ask if A4 has or intends submitting a national response to Minister Amanda Vanstone about the difficulties parents are facing with the functional assessment section of the Carers Review form. In particular, the lack of provision for parents to convey the challenges their child/children face each day living with Asperger Syndrome or PDDNOS. Some of our children are for example, able to clean their teeth. However they are only able to clean their teeth if they are prompted verbally or visually to do so. So how does one answer such a question, for surely without that external prompt the teeth could not be cleaned? There is no provision for parents to convey this problem with personal processing and planning skills. In the section on Social and Community Skills I feel there is little opportunity for parents of children with Aspergers to convey the difficulties that their child experiences in this area. There is also no provision for parents to record difficulties that arise from their child's sensory responses. One lot of parents in the ABIT membership who have a child with Asperger Syndrome, took the initiative and made side notes all the way through their review. It paid off as their allowance was continued. Many parents would not think to do this or think that it would not be allowed. There is neither provision or suggestion for extra notes on the review form.

I would be interested to know the latest and look forward to your response.

Kind Regards

Rosemary Rush – President

Autism Behavioural Intervention Tas Inc

One parent observed that “autism” can mean either “Autistic Disorder” or “Autism Spectrum Disorder”. Unless the meaning is given, you can interpret the term as you wish.

Several people commented that adding comprehensive side notes when completing the form has been effective for them: it meant they retained their allowance.

We just recently filled in our form for the Carers payment. We also made side notes and phoned up the help number. The side notes include such items as, can do sometimes when medicated, with help: can do but not adequately, also although something was able to be done we noted several points lower down that could not be done. When we phoned for help, we asked what was meant by understand a newspaper article, eg understand the words?, the content, the context or the implications. The response was 'I can read the description of understand in the dictionary!' We also asked what was meant by 'Does your child smile? We asked that our disappointment in the total inappropriateness of the form for these types of disabilities be passed on to higher personnel.

We did get the payment.

Stephen Courbêt

Re: How the loss of the carer allowance will affect our family

We have four boys, two boys with disabilities, one with Aspergers, Obsessive Compulsive disorder and Tourettes syndrome and the other with learning problems similar to Attention Deficit Disorder. We have spent a lot of money having them assessed, tested, treated and medicated and have mostly, had to pay for these services our selves.

Our boys need lots and lots of encouragement to try, to persist, to improve their efforts and behaviour in order to achieve at school, home and in society and this usually needs to be in the form of reward which costs \$\$\$\$\$\$ to be effective. Without the carer's allowance, our family would have to struggle more to pay for all of the above.

At the moment, I am not working, and it will be three more years before I will hopefully finish a degree, and be able to earn sufficient money again to provide adequate funds to support and educate our boys.

It will put a lot more strain on our family if we lose the allowance. It is the only financial support we receive to help with the boys' disability apart from a health care card each. We don't fit the criteria for any other funding at this stage.

It would make us feel really let down, totally forgotten, abandoned by the Government.
from Rhonda in Victoria

A4 ensures the Chair of the new NFCV (see above) is aware of these issues.

Letter to the ABC on Asperger's (cont.)

Following the letter (6/8/2003 in A4 Update No. 7), Dr Swan responded that he felt Tonge, et al (1999) *Behavioural and emotional disturbance in high-functioning autism and Asperger syndrome*, *Autism*, **3**(2), pp117–130 supports his assertion that “true Aspergers are often quite aggressive people”. The paper does not support Dr Swan's position because it ...

- does not mention aggression at all; it examines aggregate behaviours (that might include aggression though the paper does not say so).
- compares AS to another part of the spectrum but does not compare either group with population norms; it offers no evidence people with AS are, in absolute terms, “often quite aggressive”.

Further, Dr Swan's claim would need more support than a single paper.

Dr Swan's claim is baseless. As Dr Swan has a position of influence, his view could influence educators and employers. He could influence community perceptions thereby decreasing the social and economic participation of people with AS in the community. We suggest Dr Swan has vilified people with Asperger's Syndrome.

Following my failure to communicate adequately our concern to the producer of the Health Report or Dr Swan, in what some may see as a rigid, inflexible and possibly aggressive attitude, I complained formally to the ABC. We await an official response.