



Dear A4 members

This Update has been slow in coming because so much is happening.

A4 received a letter from the Autism Council of Australia (ACA) telling us about recent events. I hope ACA and A4 will work together on our shared goals. There seems to be total agreement that both organisations have crucial roles in improving circumstances and outcomes for people with ASD.

We've just been told the Victorian opposition is having a summit on ASD on 12/8/2003. This is an important political step for the ASD community. Congratulations to all who had a part in making it happen. Information can be found at <http://www.victorperon.com/?a1Q1Z&v3e&Nj7&4nj>.

Several general disability issues concern to our community. The proposed education standards for the Disability Discrimination Act (DDA) are important for many of our members. Issues associated with employment of people with a disability affect our some of our adult members and are a concern for families.

According to Wayne Swan, Shadow Minister for Family and Community Services, "Nearly 70,000 families nationwide who care for children with serious disabilities are threatened with the loss of the \$87 per fortnight Carer Allowance under a mean-spirited Howard Government review". He says the government intends to strip 30,000 families of this "modest allowance". This general disability issue has become a significant political wrangle. Please let us know how this affects you and how you feel about it.

And we have some news from overseas.

Several people sent us material for this Update. Thank you very much for your help. The more material I get from others, the easier is my job. Or just let me know what you would like to see in the A4 Updates.

I am particularly looking to increase the amount of information relating to adults with ASD. At present, I depend on members to provide any relevant information about issues relating to adolescents and adults ... and I'd like pass on a lot more information relevant to adolescents and adults with ASD.

regards

Bob Buckley — Convenor
convenor@a4.org.au

August 2003

A4 Members: write to a politician (continued)

In the last Update, A4 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.

I thank the members who sent a letter (or letters) and completed the form.

Unfortunately our website was down for some time so completing the form was not possible. If you are not sure, please go to the website and complete it.

To be effective, we need more active members. If you have not sent a letter, I urge you to do so. Following is a simple letter outline that you use. You can write it by hand or copy it into a new MS Word document and edit, print and post it. Or you could email your letter.

[*Your address here*]

[*Politician's full name, e.g. Mrs Kay Hull MP*]
Parliament House
Canberra ACT 2600

Dear [*Politician, e.g. Mrs Hull*],

Thank you for your interest in autism and for raising issues relating to autism in parliament.

Yours truly,

[*Your signature*]

[Your name]

[Date]

The politicians to choose from are:

Senator Susan Knowles senator.knowles@aph.gov.au	Liberal	WA
Senator Natasha Stott Despoja senator.stottdespoja@aph.gov.au	Democrats	SA
Mrs Kay Hull MP Kay.Hull.MP@aph.gov.au	Nationals	NSW
Mr Anthony Byrne MP Anthony.Byrne.MP@aph.gov.au	Labor	Vic

The politicians are from a range of parties and states so choose the one you feel most comfortable writing to. Feel free to change the words. It looks better if the letters are not all exactly the same.

Once you have sent you letter, please complete the online form at www.a4.org.au/surveys.htm so we know how many letters our members sent.

Autism Tasmania Inaugural Conference

FOCUS ON FAMILIES

The Derwent River provided a stunning backdrop for a very successful Inaugural State Conference arranged by Autism Tasmania at the Wrest Point Conference Centre in Hobart on June 20-21. There was a huge interest shown and 242 delegates registered for the one-day conference.

Ms Judy Brewer Fischer, one of the movers and shakers in the establishment of the national grassroots organization, A4, was the guest speaker at the Conference Dinner on the Friday night. Judy spoke to about 70 people about some of her family experiences as the parent of a young boy who has an ASD. She certainly struck a chord with the audience and set the tone for the conference the next day.

Autism Tasmania was pleased to welcome the Minister for Health and Human Services, Hon David Llewellyn MHA, who opened the Conference. The Minister is responsible for Disability Services, and as a result of the Conference, Autism Tasmania will shortly be meeting with him to discuss ways in which autism support can be increased.

Three well-known identities in the national autism arena were the keynote speakers for the day. Wendy Lawson spoke about keys to understanding and working with the spectrum of autism, Vicki Bitsika talked about developing a framework for effective assessment and treatment of people with a diagnosis of autism, and June Waites spoke about her book, *Smiling at Shadows*. Their knowledge, and insight into this disorder meant the each one gave a wonderful presentation to the conference.

The keynote addresses were followed by three concurrent sessions in which a number of local people presented a variety of material of a very high standard indeed. The aim of the concurrent sessions was to focus on a range of issues that affect families, and to recognize that although there are many common threads, people with an ASD, parents of young children with an ASD, parents of adolescents and parents of those in the workplace or seeking work, all seek a different perspective. Parents and professionals alike responded to a call for expressions of interest to present papers at the conference. Many had never spoken in public before, some were quite inspirational, but all provided well-considered information to the delegates. It is clear that there is a wealth of knowledge and experience of Autism Spectrum Disorder in this state. Autism Tasmania heartily thanks all the presenters for their interest and participation in the conference.

Autism Tasmania also acknowledges the excellent job done by Mick Clark, who acted as Master of Ceremonies for the day.

It would not have been possible to hold a conference without financial assistance of Commonwealth Respite for Carers. Respite was offered to members who have a family member with an ASD.

Numbers of delegates who registered for the conference exceeded our wildest expectations, and show that there is a huge demand for information and support. We are very grateful to Wrest Point, who on Friday afternoon, offered the Plenary Hall for the Keynote sessions when it was realized that 240 delegates would be very uncomfortable in Tasman Room A.

In all, the conference was a success. Autism was certainly a focus in the wider community, as a result of the great press coverage. The Minister responsible for Disability Services is more aware of the needs of this sector. And families and professionals alike have had an opportunity to share information and experiences, and this will surely make the autism community stronger.

A4 website

The A4 website, www.a4.org.au, is fully operational again. Parts were not working for a time due to technical difficulties not of our making.

Thanks to all those who wrote with suggestions and sympathy. Your advice, enthusiasm and encouragement were more assistance than technical support provided by the web-hosting service.

Autism Council of Australia (ACA)

The Autism Council of Australia (ACA) has been through some significant restructuring in recent times. Its President has written telling us ACA:

1. established a research fund
2. changed the constitution extending membership beyond the original corporate members to allow individuals and organisations to join
3. will pursue national policy issues

The [letter in PDF format](#) is on our website is on the website for downloading.

Productivity Commission

Right after I sent out A4 Update No. 6 I found out that Wendy and Peter Kiefel also made submission to the Productivity Commission. Their submissions are on the Inquiry website ([sub168.rtf](#) or [sub168.pdf](#)).

Wendy also appeared at a public hearing. Her presentation is excellent. You can download and read the transcript from the website ([RTF](#) or [PDF](#)).

Congratulations Wendy! Well done. And I encourage others to participate in these processes.

From the Daily Telegraph

SAT 09 AUG 2003, Page 2

By: LISA MILLER

A SYDNEY woman is recovering in hospital after allegedly suffocating her 10-year-old autistic son to death and then attempting to take her own life.

Daniela Dawes has been charged with the murder of her youngest child Jason, who died at their Kings Langley home on Monday morning. She allegedly admitted to police she had killed him because she was depressed and was having difficulty coping with an autistic child. She is also alleged to have told police her family – including her husband and 13-year-old daughter – “did not receive the necessary support from authorities to assist in the caring of her son”, according to police documents tendered in Blacktown Local Court yesterday.

The incident highlights the pressure on parents of autistic children, the Autism Association said yesterday. The organisation’s outreach services director Anthony Warren said while support was available for families it was often limited. “There also tends to be waiting lists for these services, sometimes hundreds of families can be waiting,” he said. “There are extraordinary stresses and strains placed on parents and families.” The association offers services including an autism intervention line, as well as a program linking parents with autistic children, he said. “But I do think in general terms there is not enough support for carers.”

According to the police documents, Dawes’ husband and daughter had left home early on the morning of the death. Dawes, who was on medication for depression, then woke Jason to get him ready for school but he was being “difficult” and would not co-operate, the documents said. “She stated that Jason then got out of bed and ran into the rumpus room.

She followed and took hold of him, pinching his nose with one hand and holding his mouth shut with the other. “She stated Jason struggled and she held him until he stopped struggling.”

She allegedly told police that she made no attempt at CPR or to call an ambulance. She said, after she dressed Jason in his pyjamas and laid him on the bed, she realised what had happened and attempted to take her own life.

She was unconscious for about three hours before her mother arrived and found her and Jason, the document said. “The accused has expressed to detectives extreme remorse,” it said.

The case was adjourned to Penrith Local Court on October 10.

TUE 12 AUG 2003, Page 8

By: VANESSA MCCAUSLAND

CRAIG Dawes, whose wife allegedly suffocated the couple’s 10-year-old autistic son, has spoken out in defence of his wife.

Daniela Dawes has been charged with the murder of her disabled son Jason after allegedly admitting to police that she had killed him because she was depressed and having difficulty coping with him.

Yesterday, Mr Dawes stood by his wife, who is recovering in hospital after attempting to kill herself. He pleaded for his wife to receive support and understanding from the public. “My wife should be fully supported and defended by everyone,” he said.

The incident, which occurred last Monday in the Dawes family home in Kings Langley, has sparked concern about the potentially debilitating stress put on parents caring for disabled family members. Mr Dawes expressed extreme frustration with the current care system. “I’ve been advised not to talk to the media or the police but given time, down the track, the public need to know what has happened ... it needs to be on the public record,” he said.

Mrs Dawes allegedly told police of the lack of support she and her family, including her 13-year-old daughter, received from authorities to care for her son. Police documents stated that Mrs Dawes was getting Jason ready for school when he became “difficult” and would not co-operate. According to the documents Mrs Dawes, who was on medication for her depression, allegedly suffocated her son by pinching his nose and holding his mouth shut until he stopped struggling.

Carers NSW president Louise Gilmore said that cases such as the Dawes’ were far from unusual. “Many in the community are in a similar state of desperation. It’s not necessarily all that unusual,” she said. “In terms of the level of desperation people get to, we talk about servicemen and women coming back with post-traumatic stress syndrome but it’s happening every day in the suburbs. Looking after someone without support absolutely leads to desperation.”

A drawn and clearly distressed Mr Dawes was at his home yesterday to retrieve his son’s belongings to take to the mortuary. Jason Dawes’ funeral will take place today.

National Draft Education Standards

For some time, politicians and state education authorities have been trying to agree on the meaning of the national Disability Discrimination and how it relates to education. Recently, the following press release appeared:

MOST STATE AND TERRITORY EDUCATION MINISTERS VOTE AGAINST DISABILITY STANDARDS

11 July, 2003 MINCO 7/03

Students with disabilities and their parents will be dismayed by the failure of the Ministerial Council on Education, Employment, Training and Youth Affairs to agree today to implement the Disability Standards for Education.

Only the Australian Capital Territory and Tasmanian Education Ministers voted with the Commonwealth to move to introduce the Standards.

The Commonwealth will therefore move unilaterally to implement the Standards to eliminate discrimination and ensure successful learning outcomes for students with disabilities and their parents.

The implementation of the Standards has been discussed for seven years. They have been delayed because some jurisdictions claim to be unsure of and/or afraid to acknowledge, their responsibilities to Australia's almost 200,000 students with disabilities. These students need to be assured of their right to participate in education and training on the same basis as other students.

The States and Territories offer wildly different assessments of the impact on their budgets of implementing the standards. New South Wales claims it will cost \$1.8 billion and Victoria \$1.4 billion to comply with the Standards, but South Australia claims just \$19.4 million, Western Australia \$15.8 million and Tasmania \$2.2 million. New South Wales claims it will need an additional 43,000 staff, equivalent to 69% of their current funding. However, the ACT does not agree it will cost anything more in that jurisdiction.

For more than seven years the Commonwealth has led the development of these Standards, consulting extensively with jurisdictions, non-government education and training providers and other stakeholders, most importantly the disability sector. I congratulate the DDA Standards Project, which represents the disability sector, for their strong contribution to the Standards.

An independent cost-benefit analysis, 'Net Impact of the Introduction of the Disability Standards for Education', has found that the benefits of the Standards far outweigh their costs. The study also found that for providers who are compliant with the Disability Discrimination Act, 1992 the costs of complying with the Standards would be marginal.

The Report of the Senate Employment, Workplace Relations and Education References Committee on Education of Students with Disabilities, released in December 2002, was strongly critical of the failure of the States, Territories and Commonwealth to reach agreement on standards for education and urged the Commonwealth to act unilaterally to bring into force the standards provided for in the Disability Discrimination Act, 1992 (DDA).

The MCEETYA's failure to agree to act on the standards is a sorry day for equality of educational opportunity.

A copy of the draft Standards and a copy of the report Net Impact of the Introduction of the Disability Standards for Education can be found at www.dest.gov.au/edu/gen_ed_pubs.htm

Analysis of issues associated with the introduction of the proposed Standards shows that several states found they are currently in breach of the Commonwealth's Disability Discrimination Act. It is especially disappointing that most states, rather than seeking to improve their performance, intend instead to continue discriminating against students with a disability.

In their analysis of costs, some states have indicated that as up to 18% of the general population have a disability, they may have to cater for a major increase in the number of students with a disability if the standards are introduced. The major component of citizens with a disability in the general population is people over 65 years old. I find it incredible that some state education authorities want to justify discrimination against young students with a disability on the basis that there may be a huge influx of primary and secondary school students aged over 65 years.

The other surprise was that state education authorities appear to be unable or unwilling to quantify the benefits of the service they provide. Their analysis of possible benefits was cursory at best.

Not learning disability. Administrative dysfunction?

A senior staff member in Education, while discussing a lack of progress in my son's education, suggested "some children just don't learn". Apparently she wanted to blame the lack of educational progress on my son personally or on his ASD diagnosis. She ignored his clearly demonstrated ability to learn: at an early age he showed he could learn by learning to walk, to feed himself, and many more complex skills.

Her hypothesis, that some children do not or cannot learn, is not supported by evidence. Research shows that any living organism can learn. Overwhelming evidence, in the form of vast numbers of journal articles, is that children make educational progress when taught properly or appropriately. For example, a blind child may not learn to see but she learns from an early age to move around without repeatedly bumping into things.

According to their diagnosis, students with ASD lack normal communication and social skills; and they behave abnormally. These ASD characteristics mean they may not learn normally; that is, like other students. Instead, their learning depends on highly skilled teachers taking different and individual approaches to instruction that are based strongly on evidence of their effectiveness. In order to ensure students with ASD benefit from their education, a teacher needs skill and experience in recognising individual learning differences and must respond reliably and effectively to the particular needs of each student.

The Executive Summary in *Educating Children with Autism*¹ concludes:

In summary, education at home, at school, and in community settings remains the primary treatment for young children with autistic spectrum disorders. Many specific techniques and several comprehensive programs have clear effects on important aspects of these children's learning. Yet links between interventions and improvements are also dependent on characteristics of the children and aspects of the treatments that are not yet fully understood. The challenges are to ensure implementation of what is already known so that every child benefits from this knowledge and to work from existing

¹ National Research Council, Committee on Educational Interventions for Children with Autism, Catherine Lord and James P. McGee, eds (2001) *Educating Children with Autism*, National Academy Press, Washington DC, p9.

research to identify more effective educational interventions for all children with autistic spectrum disorders.”

Education authorities in Australia rarely recognise or admit that students with ASD, because of their learning differences, require specialist teachers. The administrators are unwilling or unable to accept that these students get little benefit from the education provided unless a substantially different instructional approach is used. Different students need different instructional elements and learn in different ways. A child who cannot attend to group instructions from a teacher cannot follow those instructions and, in the absence of other teaching methods, will not learn as intended. Few teachers have the knowledge, skill, experience and support they need to teach students with ASD comprehensively.

Typically, education administrators blame the teacher if they can't blame the student. A lack of progress in a student's learning might be explained as a *teaching disorder*. Quite unreasonably, administrators expect teachers to assimilate massive knowledge and skill through the minimal professional development they provide.

Australia provides very limited opportunities for teachers to develop knowledge of and skill in best practice teaching for students with ASD. Such knowledge and skill comes from extensive specialist training, not from short workshops and conference attendance. Only a few researchers in Australia have sufficient interest in ASD and the knowledge needed to instruct teachers who specialise in ASD. Comprehensive courses for teachers who teach students with ASD are rare.

Despite, dramatically increasing numbers of students with an ASD diagnosis, education authorities are not planning timely development of sufficient specialist staff to address the educational needs of the growing number and variety of students with an ASD.

Is failure to meet a student's learning needs, including providing sufficient specialist training for teachers, *administrative dysfunction*? Administrators in education should recognise that a student with ASD who is not learning has educational needs that are different from those being provided. A student's success in learning depends on a situation that meets all the student's needs including a teacher or teachers with specialised knowledge, skills and experience.

Letter to the ABC

The following letter was sent on 6/8/2003. The ABC has not responded to the issues yet.

Ms Brigitte Seega
Producer -- ABC Health Report

Dear Ms Seega,

The transcript of an interview on the Health Report with Professor Mark Dadds by Norman Swan (28 July 2003) can be found on the ABC website. The URL is <http://www.abc.net.au/rn/talks/8.30/helthrpt/stories/s907642.htm>

The latter section of the transcript contains the following:

Mark Dadds: Yes, and to help them to actually attend to people's faces, to care about what other people think and show some kind of empathy. Now there's a big literature growing on what years we learned the building blocks of empathy. There is some material coming out indicating that you actually can make a difference in young children's lives to their ability to feel and express empathy.

Norman Swan: So presumably these kids are also the ones who are mislabelled autism spectrum disorder sometimes?

Mark Dadds: This is an interesting issue. I remember with Martin Bryant there was a big debate over whether he had an autistic spectrum disorder or whether it was a conduct disorder. Generally, autistic spectrum disorder kids are not kind of overly aggressive and predatory like that, so we wouldn't want to worry too much about –

Norman Swan: Although they say that the true Aspergers is quite an aggressive person and often the Aspergers are mislabelled as the kid who's got mildly autistic behaviour and not showing much emotionality or receptivity to others. Often a really nice kid who does well, and they're often mislabelled Aspergers, and true Aspergers are often quite aggressive people.

Mark Dadds: I've certainly seen a number of Aspergers kids that are quite aggressive, especially when they hit the teen years. It can be quite worrying. But I suppose I wouldn't want to worry all the people out there involved with Aspergers and autism that I'm talking about those particular kids. But we definitely are talking about an overlap in ideas, and that is that they have difficulty understanding other people's faces and emotions. Now if you've got that in combination with a kind of predatory aggression, then I think that's the key.

In the question quoted above (the first of his quoted utterances), Norman Swan asserts children are "mislabelled autism spectrum disorder".

1. What evidence does the the ABC have that children are being "mislabelled" in this way?
2. Who does the ABC claim is doing this mislabelling?

Norman Swan appears from the transcript to cut off Professor Dadds in order to present his own contrary view. At this point, Norman Swan does not ask questions. Instead, he makes a series of statements linking Aspergers (herein deemed to mean Asperger's Syndrome) with aggression. As Norman Swan's views vary significantly from a considerable body of published research and expert opinion (and from my own limited understanding), I am bound to ask the following questions.

1. Does the ABC regard Norman Swan's behaviour in this instance as appropriate conduct in an interview?
2. Who is "they" in Norman Swan's statement "they say that the true Aspergers is quite an aggressive person ..."?
3. What evidence does the ABC have to support Norman Swan's statement that "often the Aspergers are mislabelled as the kid who's got mildly autistic behaviour and not showing much emotionality or receptivity to others"?
4. What evidence does the ABC have to support Norman Swan's assertion that people are "often mislabelled Aspergers"?
5. The diagnostic criteria for Asperger's Syndrome (see DSM-IV and ICD-10) do not mention "aggression". What is the basis for asserting that "true Aspergers are often quite aggressive people"?

6. What relevant qualifications, knowledge and experience has Norman Swan in the diagnosis of autism spectrum disorder, particularly Asperger's Syndrome?

yours sincerely

Bob Buckley

Convenor -- Autism Aspergers Advocacy Australia

Employment Issues

The Media has shown some recent interest in the subject of employment for people with a disability. Some of this centres on matters described in the following Democrats press release.

Govt hypocritical over Disability employment

The Government's call for Australian employers to be good corporate citizens and employ more people with disabilities is grossly hypocritical given the drastic reduction in such positions now available within government organisations.

Minister Vanstone today announced the Prime Minister's annual Employer of the Year Awards, saying that 'employing a person with a disability not only makes sound financial sense, it signals to the community that a business is a good corporate citizen'.

According to the Workplace Diversity Report 2001-2002, there has been a consistent decline in the employment of people with a disability in the Australian Public Service, both as a proportion of APS employees and in absolute numbers.

Australian Democrats Disability spokesperson, Senator Brian Greig, says the overall drop in positions for people with disabilities available in the public service shows what a poor role model the government is.

The Report states that 'The number of people with a disability employed has declined from 8092 at June 1993 to 4056 at June 2002, while the proportion declined from 5.7% at June 1993 to 3.9% at June 2001, with a further small decline to 3.6% in June 2002.'

"The Department of Prime Minister and Cabinet has an equally dismal record in this area by employing only 2.7 per cent," Senator Greig said.

"The Government should put its words into action by providing more employment opportunities for employees with disabilities.

"It's one thing to suggest everyone else should be good corporate citizens, but with around 20 per cent of the Australian population having a disability, the Australian Public Service's record of 3.6 per cent employment is a disgrace," Senator Greig said.

The contents of this press release are like the curates egg: good in parts. It is important to raise concern over the decline in people in public service with a disability from 5.7% to 3.6%.

The information used in political decisions, policy development and planning of disability services is frequently misleading or wrong. In this instance, while almost 20% of the population have a disability, a high proportion of those with a disability are people past retirement age. The proportion of people seeking employment who have a disability is significantly below 20%. Employment issues for people with a disability are a significant yet manageable problem for government.

The government employees should include at least a representative proportion of people with a disability. The decrease from 3.9% to 3.6% in a year is not a small decline. It is in fact a faster decline than the annual rate over the 1993 to 2001 period. It seems the reducing government employment of people with a disability is part of a distressing if not alarming trend.

Overseas News

Canada: autism, government and court

The B.C. government in Canada is taking a decision of the B.C. Court of Appeal to yet another level. The Supreme Court of Canada has agreed to hear a landmark case involving the right of judges to direct how health-care money should be spent.

B.C. courts ordered the province to provide intensive treatment for autistic children. Siding with four sets of parents who had been denied an effective therapy for their children with autism, a 2-1 appeal court majority said they had no choice but to forcibly reorder government health-care priorities. The B.C. judges made it clear that when constitutional rights and the welfare of children are at stake, governments lose their monopoly over budgetary decision-making.

Not content simply to order intensive therapy, the B.C. appeal judges awarded the parents 'symbolic' damages of \$20,000 each. They also stressed that they are prepared to enforce their order if the province fails to follow through with proper therapy. The B.C. ruling infuriated critics of judicial activism and gave renewed hope to those who believe activist judges can prevent penny-pinching legislators from making minorities absorb the brunt of their budget-cutting.

"This case is obviously of great importance to the parents and their children," constitutional lawyer David Stratas said. "But governments who face competing demands from many groups, are looking closely at it too. This is about a right to health care. It is a significant step forward."

Mr. Stratas said the Supreme Court's ruling will provide an important signal about its current thoughts on how fully the courts should throw themselves into modifying government priorities that offend the Charter. "Is it appropriate for courts in effect to order government to supply funding in order to eliminate rights violations?" he said. "Or, is funding a central task of the legislature — and all courts can do is declare rights breach and leave it to the legislature to design an appropriate response?"

Autism is a neurobehavioural syndrome that affects 10 to 15 out of every 10,000 children. Symptoms, which include disordered thinking and erratic behaviour, typically appear when children are two or three years old. Left untreated, most autistic children are doomed to a lifetime of social dysfunction and isolation. Many end up being institutionalized.

Funding of autism therapy varies from province to province, and gaps in treatment have spawned several class-action lawsuits. Many children with the diagnosis get little or no treatment.

David Corbett, a Toronto lawyer battling the Ontario government over autism in one suit said recently that he hopes the B.C. decision induces other provinces to do "the right thing" and stop putting money ahead of children's health. "I think the court is saying that it is very difficult to draw the line on health-care services, but that leaving this service out was just plain wrong," Mr. Corbett said.

The B.C. court specified that the province must supply funds for Lovass Autism Treatment, an intensive and time-consuming technique that is considered the most effective therapy available. "Having created a universal medicare system, the government is prohibited from conferring those benefits in a discriminatory manner," the court said.

The ruling is rooted in equality guarantees enshrined in the Charter of Rights as well as the inherent duty of courts to look after the interests of children. The court said that the province failed to justify treating autistic children as if they were 'less worthy' of medical assistance than non-autistic children. "It is to say that the community is less interested in their plight than the plight of other children needing medical care and adults needing mental-health therapy," Madam Justice Mary Saunders and Mr. Justice John Hall said.

While they expressed sympathy with government arguments that the courts ought not to be dictating health-care priorities, the judges said that the consequences of not treating autism in a timely manner are unacceptably grave.

Adapted from *The Globe and Mail*

From: ASA-Net, The Autism Society of America's e-Newsletter, July 15, 2003

Autism Caucus and ASA Hold Education Briefing

On July 10, leaders of the Congressional Coalition for Autism Research and Education (CARE) and the Autism Society of America held a joint briefing for Members of Congress and their staff. The purpose of the briefing was to educate Members of Congress about autism and to address the important role legislation plays in improving programs and services for individuals with the disorder.

ASA representatives kicked off the briefing with an overview of autism, which included a visual presentation highlighting the dramatic growth in the prevalence of autism over the last decade and the expected rise in the cost of autism over the next decade. They also provided personal perspectives on the difficulties of raising children with autism and the importance of access to education and other support services.

The Caucus leaders addressed the importance of educating the public and Members of Congress about the ever-growing cases of autism and the need to support legislation that provides educational and support services for those with autism. Caucus leaders also talked about the different key roles the Individuals with Disabilities Education Act (IDEA) plays in helping to ensure that children with autism receive an appropriate education. In addition, they also addressed the importance of training for teachers, which is provided for in the Caucus's proposed Teacher Education for Autistic Children Act (TEACH). The Congressmen also acknowledged that the language in IDEA is complex and vowed to continue to help families better understand how the educational rights to which their children are entitled.

Jeff Sell, ASA 1st Vice President and Chair of the Government Relations Committee, provided an overview of the autism crisis across the country through a presentation of ASA's new charts dramatizing the growth in autism. Sell also offered a personal look at autism for the audience, many of whom had little or no first-hand knowledge of the disorder, by sharing the difficult reality he and

his wife face raising twin boys with autism. He explained, "One of our twins is nonverbal, so we have never heard him say, 'I love you,' because we have never heard him say anything."

"But there is always room for improvement, and we improve through learning," Sell said. Referring to IDEA and the proposed TEACH Act, Sell said: "Individuals with disabilities deserve a free education in the least restrictive environment with the best-trained teachers available; no one should be denied an opportunity to learn."

For more information about the July 10 briefing, please [click here](#).

Tips to Ensuring a Successful Positive Behavior Plan

IDEA requires a child's Individualized Education Plan (IEP) team pay special attention to a child's behavior if it gets in the way of his or her education or the education of others. The IEP team must consider the use of positive behavior interventions. Get a good idea what a positive behavior plan looks like by viewing sample plans for students with ADHD, autism and Asperger's Disorder online at the Web site listed below. In addition, that site has a form to help you through the process of writing your own plan.

You can use this information along with another publication, "Positive Behavioral Interventions: Parents Need to Know," published by the Families and Advocates Partnership for Education (FAPE) project. This is a curriculum consisting of 89 color transparencies along with trainer information. "Positive Behavioral Interventions: Parents Need to Know" is available in Spanish as well as English.

These transparencies and training materials were developed at PACER Center by FAPE and the Technical Assistance Alliance for Parent Centers (Alliance). They are available for free downloading online by [clicking here](#).

Advocates for Special Kids has a Web site at www.advocatesforspecialkids.org.

The Pacer Center's FAPE coordinating office, has a Web site: www.fape.org.