A4 Autism Aspergers Advocacy Australia

Commissioner Helen Owens
Presiding Commissioner
Inquiry into the Disability Discrimination Act 1992
Productivity Commission
Locked Bag 2, Collins Street East
Melbourne VIC 8003
(Email: dda@pc.gov.au)

Dear Ms Owens,

Subject: **Draft Report of the Inquiry into the Disability Discrimination Act**

Thank you for the opportunity to comment on the Draft Report into the Disability Discrimination Act 1992 (DDA).

Many significant outcomes for people with disabilities may well be due to the DDA. But the DDA and the legal system do not protect children with autism. The DDA does not offer and does not provide a fair go for Australian children with autism. The prognosis for the growing number of Australians with Autistic Disorder is extremely poor. The prognosis for the families of people with autism is poor. Many families close their businesses and downgrade their jobs. Family members have high risk of mental illness.

Attachment 1 is recent media material, sparked by the death of Jason Dawes, relating to children with autism in NSW. This material describes the situation of families all around the country.

A lesson for Ken

Ken is quiet and aloof. He has autism and very little use of language. One day at school, another child took a toy from Ken. Ken rushed up and took the toy back and in the process knocked the other child off his feet. The classroom staff saw this happen … and rejoiced, then reinforced and encouraged Ken's violent assertiveness. He learnt that lesson well.

Ken's school taught him, when he was 6 years old, violent behaviour is effective in getting what he wants. His education was that violence gets you what you want (plus rewards!) and language use can be avoided.

Ken's family, especially his younger sister, now live with his violence every day. As Ken grows, the community suffers the consequence of Ken's lesson in violence. But people do not know Ken's history and who taught him to behave violently — so Ken and his family are blamed.

Early in 1997, Joe's family sought to protect Joe's rights to treatment and rehabilitation for his autism, and an effective education given his level of disability. They were advised professionally that the DDA offered Joe very little protection. They were told the ACT Discrimination Act offers better protection of Joe's rights.

At the end of 2003, the complaint that Joe was not provided with effective treatment and education for his autism is still in the process of being heard by the ACT Discrimination Tribunal. Whatever the outcome, Joe cannot receive the early intervention he needed to become a functional citizen. Whatever the result of the complaint, it is now too late for Joe to access early intervention: the DDA and similar instruments do not protect Joe's right to treatment and rehabilitation for his autism, which is a clinical condition.

No protection for Jim

One day, Jim arrived home from school with severe bruises across his back and all down the back of his legs and arms. Immediately, his mother took him to the police station.

The police asked him what happened. Jim couldn't tell them. Jim has autism. He is non-verbal. He has not been taught how to communicate.

Jim could not answer police questions. The police interviewed staff at the Jim's school. No one knew (admitted) anything about Jim's bruises. The Education Department accused Jim's parents. The police ceased their investigation without obtaining further evidence and without any resolution.

Physically, there is nothing wrong with these boys. They are, and appears to be, fully functional children. Everything works except for their behaviour: unknown parts of their nervous systems do not function normally.

People do not understand them and their needs. Consequently, they are incredibly vulnerable. The health and early childhood systems in Australia did not offer them an effective form of rehabilitation for their autism. The education system unintentionally and inexpertly teaches them violent and challenging behaviours that their families subsequently have to live with.

These boys will need round the clock supervision for the rest of their lives. There is little chance they will live independently. They are at significant risk of developing severe mental illness and other major health problems that may not even be detected (since they are not given effective rehabilitation for their communication dysfunction).

Substantive equality does not give a fair go to everyone. It is not an appropriate model for people, especially children, with severe or profound disability. Ken, Joe and Jim do not understand opportunity and competition. They will never compete effectively in any circumstance.

In relation to autism, the DDA leaves the community with the considerable cost of supporting these boys and their families for much of their lives. Your productivity Commission Draft Report, in its Key Points, says "there is not enough information to quantify these costs and benefits". We believe there is sufficient information to accurately quantify the costs and benefits in cases like these. We observe that the government and its agents oppose attempts to do so or dispute anything contrary to the prevalent economic dogma.

But don't worry. The boys and their families consume resources and support services thereby contributing disproportionately to measures of the nation's economic activity. And who cares that the nett outcome is unproductive and anti-competitive.

Currently, the government is in active denial of anything to do with autism (see Attachment 2). But denial does not eliminate the problem autism poses. The autism diagnosis rate is around 1% of the birth-rate in most states and regions (a fact supported by significant amounts of data that the government chooses to ignore). The outcome in Jason Dawes cases is extreme, while Joe and Jim's cases are more representative of children with Autistic Disorder, a group who make up a substantial component of the autism spectrum.

We are disappointed that the Draft Report does not heed the submissions received and evidence presented relating to autism. A number of submissions describe how the DDA and its implementation fail to protect the rights of people with autism and related disorders. The Draft Report shows no signs that these submissions made any impression.

The Draft report says the DDA does not protect people with a disability or their associates from vilification. We believe the DDA should protect people with a disability from vilification. Attachment 3 is the outcome of a complaint to the ABC over vilification of people with Asperger's Disorder. This incident has the potential to adversely affect the education and employment of people with Asperger's Disorder. The ABC's Code of Practice offers no protection; nor does the DDA.

Please try to understand that autism is a distinct disability that affects communication, social skills and behaviour. Especially, it is distinct from intellectual disability. Failure to appreciate the distinction seriously disadvantages people with autism.

We ask that you review the material you received relating to autism and the DDA then reconsider and revise the relevant parts of your report to address issues affecting people with autism.

In the event that you make no changes relating to our concerns, people on the autism spectrum and their associates feel they deserve an explanation for the omission from your report of issues that affect people with autism. Specifically, they seek to understand why the Inquiry Report does not recommend the DDA should:

- clearly ensure (at least) children with a disabling clinical condition can access effective treatment and rehabilitation that minimises the disability due to their clinical condition;
- offer an accessible complaints process at the national level for people with a disabling condition; and
- prevent vilification of people with a disability and their associates.

Please feel free to contact us.

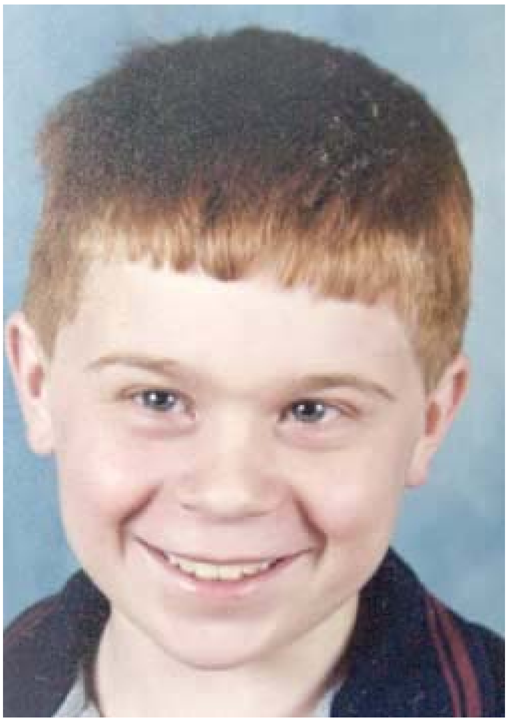
yours sincerely

Bob Buckley
Convenor

Attachment 1

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 and 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.

Massive pressure

By TORY MAGUIRE

13aug03

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.

Unspeakable sorrow

By VANESSA McCAUSLAND

13aug03

A SOBBING Daniela Dawes, ringed by police and prison officers, yesterday did the unimaginable and buried the autistic son she is alleged to have murdered.

Released from jail for the ceremony, she watched as 10-year-old Jason, who died last Thursday, was put to rest.

It is alleged that Dawes, frustration overwhelming her, suffocated her son at the family's Kings Langley home.

Yesterday the Dawes family and friends were torn by a tragic double dose of grief as they tried to come to terms with Jason's death and the traumatic circumstances surrounding his mother's imprisonment.

Many of them are behind Dawes, with Jason's uncle Darren saying: "The family is standing by Daniela 100 per cent. Everybody's got some feelings, of course, towards what has happened, but . . . for 10 years these people cried for help and it just didn't come."

Jason's father, Craig Dawes, comforted his wife silently, beyond words at the sight of the boy's tiny white coffin flanked by teddy bears, balloons and flowers.

On leave from Mulawa Women's Detention Centre at Silverwater, Dawes looked stunned and downcast as she filed into the Leppington chapel, which was brimming with tearful mourners.

Her wrist bore the bandage that told of her struggle – she is said to have tried to take her own life after Jason's death.

Darren Dawes – Mr Dawes' elder brother – hinted at the division and confusion among family and friends over the tragedy.

"There are a lot of people in there who will take a long time to get over this, but at the same time there are a lot of people who will absolutely support the Dawes," he said.

Detective Senior Constable Steve Dempsey, who was at the funeral, described the family's emotional position as tenuous.

"The family could erupt. The whole situation is very volatile," he said.

But it was also a day full of love.

Jason's 13-year-old sister Alana made a brave and moving eulogy for a brother she loved and misses.

Tears flowed as Eric Clapton's heart wrenching ode to his own son's death, Tears in Heaven, rang through the chapel.

The ceremony ended with young cousins and friends joining Alana in sending a dozen red, white and blue balloons into the sky to the words, "Fly through the fields, be on your way, don't wait for me."

Darren Dawes spoke of the love and sorrow that poured out as Jason was remembered.

"Jason was a lovely little boy," he said. "Unfortunately, he couldn't speak and he was autistic.

"He was a bundle of nerves and a bundle of activity. If you can understand this young fella running around all day, every day, 24 hours on the go except for when he was sleeping . . . that's what they had to work with," he said.

"But no one has a sense of relief that Jason is gone. It's devastating for the family."

Darren said he and his brother Craig were angry at the situation the family had been placed in.

"There’s a lot of anger because people don’t understand every circumstance. They don’t understand all the facts and details, but there’s also a lot of anger towards the Government and the system that has let Daniela down," he said.

The family plan to fight Daniela’s charges fiercely.

"We are now into defensive mode. She’s not guilty of any of the charges that they’re putting forward," he said.

Feedback from 13Aug03

From: David Isaac
Comment: It is very difficult to condemn anywone for an action that has been committed without being able to put yourself in the same kind of situation. There is only so much sufferring and anguish a person can take before they can lose their sense of what is right or wrong. I cannot honestly blame Daniela Dawes for what she has done.

From: Katrina
Comment: its only really a matter of time till families tear apart because of autism, the stress ,the cost to siblings 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 cannont 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, goverment 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.. ,

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From: Christopher
Comment: Why are you making a media circus of this tragedy ? There are no winners except the media. Leave these people alone.

From: Mitchell's Mum
Comment: What an injustice! Get this poor woman out of jail. She will already be there for the rest of her life emotionally...Why don't we try to understand how this tragedy happened in the first place rather than sweep it under the carpet??? my heart goes out to Daniela & her entire family. I also have a son with Asperger's Syndrome who I love with my entire being!!!!

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: Samantha
Comment: I was at the funeral of Jason Dawes yesterday and I was totally disgusted in the fact that reporters were even there! This is a very difficult time for the family and that was something they just did not need at this moment. It's a shame you don't have a little more compassion towards people.

Accused mum isolated

By VANESSA McCAUSLAND

14aug03

DANIELA Dawes, who has been charged with murdering her autistic son Jason, is in Long Bay Jail’s medical wing, cut off from all communication with her husband Craig and desperate to see her 13-year-old daughter Alana.

Daniela’s brother-in-law Darren Dawes spoke yesterday of Daniela’s desperate state, away from the people she loves.

"She’s absolutely shattered," he said.

"Craig can’t even make phone calls in.

"You’ve got this woman who was having problems in the first place and is now having her support network removed from her by being placed in Long Bay."

Daniela is reportedly pining to see her daughter Alana.

Mrs Dawes allegedly suffocated her 10-year-old autistic son on Thursday in the family’s Kings Langley home after finding him "difficult to deal with".

She allegedly told police that she held him until he stopped struggling and did not attempt CPR, later allegedly attempting to take her own life.

The plight of a parent struggling with caring for an autistic child inspired dozens of letters to the Telegraph yesterday, empathising with a mother’s pain.

Let Daniela out

By VANESSA McCAUSLAND

15aug03

THE family of Daniela Dawes, who is accused of suffocating her 10-year-old autistic son Jason, are calling for her to be freed from jail.

They are angered that NSW is the only state in the nation that does not have a maximum security health-care run facility outside the prison system for sensitive cases such as Daniela’s.

Mrs Dawes is in Long Bay Jail hospital, charged with murdering her son Jason, after allegedly finding him "difficult to deal with", in their Kings Langley home last week.

Daniela's brother-in-law Darren Dawes said the facilities at the jail were totally inappropriate for her need for care and support.

"It's not a place we can take her daughter Alana. She wants to desperately see Alana and it's not the type of place you want to take children. I've been in there and seen it," he said.

"Whilst we understand the gravity of the situation and how tough it is, it's still an entirely difficult place for her to be. And that's where it's just wrong.

"If she was in Victoria or even Queensland there would be other facilities she would be in, being taken care of in a better way. That makes us feel quite cranky. I mean, why does it have to wait until there is a tragedy until people start to see shortfalls?"

Shadow minister for community services John Ryan said yesterday that Daniela Dawes should not be in jail.

"In any other Australian state or in New Zealand, people who were in the same situation as Daniela Dawes, would not be in jail, cut off from her family," he said.

"This is because NSW has still not yet built and opened a hospital, outside the prison system for forensic mental patients, Mr Ryan said.

"If this incident occurred in Victoria, for example, as soon as she was charged Daniela would be taken for assessment and treatment in their 10-bed purpose built women's unit at the maximum-security hospital

Mr Ryan said that the difference between the two modes of care was having nurses instead of guards, specialised treatment not just custody, more access for family and not having to wear prison green uniforms.

Such a facility is reportedly being built in NSW but it is believed that it will not be ready until 2005.

Health Minister Morris Iemma's office refused to comment about the issue yesterday.

Senior Assistant Commissioner of Inmate and Custodial Services Ian McLean said the Long Bay Hospital could only accommodate visits during weekends in Daniela's case.

The plight of a parent in jail after struggling with the weight of caring for an autistic child has inspired dozens of letters and e-mails to the Daily Telegraph.

E-mails from readers' hearts

What an injustice! Get this poor woman out of jail. Why don't we try to understand how this tragedy happened in the first place rather than sweep it under the carpet?

Michelle

I have two autistic children. It is a fine line between sanity and insanity when you care full-time for autistic children – there have been times when, without the support of my husband and other children I could have been in Daniela Dawes shoes. Help is basically non-existent

Julie

I have cried for Jason and Daniela and for the life of me cannot understand why this poor women has been placed in a prison cell. I know she ended Jason's life but she needs caring, understanding and support not persecution. I'm so glad that Daniela's husband has so publicly given his support and hope that others will follow

Delores

I felt tears well up in my eyes when I read the story of Jason Dawes and his family. Unfortunately, the sense of isolation that comes with caring for a child with autism is all too frequent for parents in this situation. We too, have a little girl with autism and the pressures my husband and I have faced over the last nearly four years have been enormous, and beyond what any typical marriage could survive. We are still together, but only after a great deal of personal counselling

Charmain Leone

As a parent you put on a brave face, but you grieve all your life, like a burning pit at the bottom of your stomach. Poor, Jason, poor Daniela . . . what a tragedy

Rita

My daughter is nine and she has autism. There is just not enough support in terms of respite for carers who deal with a child with a disability like autism. I feel very sorry for Jason Dawes' mother to think she felt so helpless and desperate and put in a horrible situation like this

Anonymous mother

Perhaps this death will start to get the ball rolling, I hope so . . . nothing we are doing seems to make the government take heed. Early intervention with an intensive program is the only answer

Kathryn Eardley-Wilmot

How much more this woman and her family need to suffer? What danger is she to our community? Where are our priorities? there are plenty of child rapists let lose in the streets and the prosecution concentrates on persecuting a mother who needs help

Katia Falco

Who is going to stand up for this woman hasn't she been through enough already? She needs help before it's too late. Real criminals get away with murder and this poor woman should be with her family. Get her released today.

Deborah Fay

Neither help nor hope in family grief

15aug03

IN HOMES across the state parents wept for a 10-year-old boy whose clinically depressed mother is accused of smothering him to death before attempting to take her own life. **HELEN McCABE** writes.

Anyone who has ever raised a difficult child or lived with someone with a disability was overcome with grief.

As the eldest child of a farming family where one of my three brothers was born with cerebral palsy, the case of Daniela Dawes and her son Jason provoked deeply held emotions and unease.

How could any parent reach the point where he or she holds a hand over a child's mouth until he stops struggling.

Autism and cerebral palsy both affect the way a child walks, talks and plays, with varying degrees of severity.

Both are linked to the mysteries of the brain.

In the 1950s and '60s there was a misguided belief bad parenting was to blame for the unpredictable, unruly behaviour of an autistic child.

While medical understanding has improved, society's levels of tolerance and assistance have not.

For reasons unknown, four times as many boys than girls suffer autism – and the number of sufferers is growing.

Sufferers are prone to repetitive, obsessive behaviour, extreme levels of energy, difficulty with language and often sleep very little.

They can just as easily be intellectually gifted as have a low IQ.

Both autism and cerebral palsy are conditions which respect no socio-economic or geographic boundaries – there are no cures.

My brother was barely walking when doctors decided to proceed with a painful operation that confined him to a specially configured hospital bed with plaster on both legs stretching from his ankles to his thighs.

His disability is mild and he is living a life of achievement as he pursues sporting, academic and professional goals far beyond the expectations of many whose ignorance continues to frustrate and humiliate carers and families.

Among the reader responses to the story of Daniela Dawes were some that demonstrated continuing ignorance and lack of tolerance for children who are "different".

This intolerance is one of the most stressful and humiliating factors in the daily life of a parent trying to raise a "different" child.

Others understood.

Through tears, reader Colleen Radley explained why she abandoned shopping with her three-year-old son.

"My husband would come home from work and find me crying in the corner with my son running riot," she said.

"I have cried more tears in the last three years than most people do in a life time.

"Somehow I have found the strength to keep going and my son is starting to do alright.

"I have been abused by people in the shopping centre [telling me] to control my son.

"My husband and I don't even sleep in the same room as I sleep with our son.

"My heart goes out to Daniela Dawes and family as I know where she is coming from, your heart just breaks for these kids and their families."

Leeta Spinola admitted to extreme levels of frustration and her reliance on medication to help in dealing with her eight-year-old son.

"I take Zoloft to help me keep in control and not let matters reach desperate measures," she said.

Among the parents and siblings of special-needs children grappling with Jason's death were Tim and Judy Fischer.

Their nine-year-old son Harrison now catches the bus to and from school.

The former deputy prime minister said it was his wife who had borne the brunt of their son's autism.

"I can tell you every family in Australia who has a child with special needs wants to go and help this family get through this," Mrs Brewer Fischer said yesterday.

As she struggled to think about anything else yesterday, Mrs Brewer Fischer reflected on how the Dawes' story had highlighted a desperate community need for government assistance.

Not more help – any help.

"It's not that they don't get enough help, I meet families who get zero [assistance]," she said.

"When we were told that our son had autism I expected that there would be some sort of system swing into action and there were be options – none of that happened.

"There are early intervention programs but it can take up to two years for it be diagnosed and the waiting lists for early intervention programs for three to five year olds take 18 months.

"By the time a place comes up the child's aged five."

If and when blame is levelled in the case of Jason Dawes, please let it include the system – and may help begin to flow to those most in need.

mccabeh@sundaytelegraph.com.au

From: John
Comment: As a father of an autistic child i find it incredible that this women has been cut off from her network of family when she needs them most. The authorities are quite happy to intervene when an offence is commited but shunned this mother when she was at her wits end. Wake up John Howard...Stop looking overseas at terrorism ...look right here.. this women and child may have been saved if there was funding and support services made available to genuine Australians...Stop overseas funding NOW ...We need help here.

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

Autistic empathy abroad

By VANESSA McCAUSLAND

16aug03

A NEW Zealand mother who killed her 17-year-old autistic daughter and inspired changes to the law in her country is giving new hope to the family of Daniela Dawes.

Mrs Dawes allegedly suffocated her autistic 10-year-old son Jason last week after finding him "difficult" to deal with.

She was released from Long Bay jail to attend her son’s funeral on Tuesday.

In a similarly tragic case five years ago, New Zealand woman Janine Albury Thomson was charged with the strangulation murder of her 17-year-old daughter Casey.

In October 1998, Mrs Albury Thomson was tried for murder but convicted of manslaughter.

Her original sentence of four years was so fiercely contested by the public that the Court of Appeal reduced her sentence to 18 months.

Mrs Albury Thomson was released after serving five months.

The case has breathed hope into the mourning Dawes family. Daniela’s brother-in-law and Jason’s uncle Darren Dawes said yesterday he had not heard of the case and that it was good news.

"That gives you hope. It’s not Australian law but it’s good to hear that this can come about – yes, it does give us hope," he said.

The case resulted in a New Zealand government inquiry. Autism New Zealand president Chris McGuire said the case changed the face of autism care in the country.

"There were immediate increases in funding for services," he said.

"The Government agreed to a big education program for those who look after children with autism. It also funded a program for specialist teachers and another program called Early Bird – an English program for parents of children newly diagnosed with autism.

"It gives them management skills and shows them how to understand and educate their child."

Darren Dawes said: "It shows these things have to be recognised and fixed – this is obviously not just Australia-wide – it gives credence to what we've been saying all along."

Dawes family friend Kris Cook spoke of Daniela's mental condition yesterday: "Daniela needs mental help – and she needs it now."

The Daily Telegraph, Edition 1 - State SAT 16 AUG 2003, Page 026

Sacrificing everything for a child

By: *VANESSA MCCAUSLAND*

Families are devoted to supporting their loved one with autism but they are also crying out for help. VANESSA McCAUSLAND reports

Like so many mornings before, Daniela Dawes rose on Monday to face the routine of dressing and preparing her 10-year-old autistic son Jason for school. The mother-of-two allegedly followed Jason as he ran, like the energetic little boy he was, from his bed into the rumpus room.

Daniela, 38, who had been on medication for depression, told police in her statement Jason was being ‘‘difficult” and would not co-operate.

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

She then dressed her son in his pyjamas and laid him gently on the bed. And, according to her statement to police, when she realised what had happened she tried to take her own life.

Daniela’s life was Jason. He was not like other children. His autism meant he had an obsession with shutting car doors -- even if it meant running blindly across a road to do so. He was a bundle of nerves and activity. Jason also had disprexia -- the inability to produce speech.

At Jason’s funeral, his uncle Darren Dawes spoke of the heartbreak the family felt.

‘‘Picture now in your mind Jason saying your name for the first time and the smile that it would bring. For this is something that Craig and Daniela would never hear or see. I picture him now being free from autism and saying the words ‘I love you, Mum and Dad for I am now free and no longer confused’,” he said.

Daniela and her family seem to be the tragic victims of a frustration and pain that has been seething beneath the surface for years. But the funeral speech also demonstrated there is also enormous joy and beauty in a parent’s dedication to their autistic child.

‘‘Jason was an active boy who loved to hear people sing. His laugh was infectious and as all boys do, he loved to wrestle with his dad,” said Darren. ‘‘Some of my fondest memories of him are keeping his mum and dad fit by constantly being on the go. Craig ran more after Jason than he did in playing 10 years on the football field.”

Jason Dawes adored music. He clicked his fingers along to the tune because he couldn’t sing. The Dawes, like so many families, made the most of what they had. But it just wasn’t enough. As Darren Dawes went on to say at that heartbreaking funeral, ‘‘I believe Jason now plays in a better place, free from ridicule, free from the stares, free from autism.”

Ridicule and lack of understanding pervade the lives of parents with autistic children.

Suzan Reid is a single mum from Croydon Park caring for her eight-year-old autistic son, Brodie.

‘‘These kids look normal and when they are naughty and scream and carry on in the supermarket, everyone looks at you as though you can’t control your kid,” she says. ‘‘They don’t understand that autistic children are run by routine. They freak out if something changes.”

Many of the women Reid knows with autistic children are depressed, as it appears

Daniela was.

‘‘I’m a pretty strong person,’’ says Reid. ‘‘I’m not on medication for depression but I could be the same as Daniela Dawes.’’

Brodie has run away from home and school 12 times.

‘‘Once he got from Homebush to Five Dock -- he would have had to cross Parramatta Road. Each time I think, this is it -- this is going to be the end of him. You crack with the stress of losing him,’’ she says.

‘‘He’s such a very special child and I’m glad I had him because [without him] I wouldn’t be the person I am today.’’

Rachel Manning from Mount Pleasant is discovering the challenge of having a teenage daughter with autism and epilepsy. She and her husband Mitch have had the police at their home in recent nights after neighbours suspected they were abusing their 16-year-old daughter, Belinda.

‘‘We had to send a letter around explaining that we were not abusing her,’’ she says.

‘‘We have people come out and look when she is screaming and chucking a tantrum. Sometimes it lasts two hours.’’

The Mannings have three other children who bear the brunt of their sister’s aggression.

‘‘We can’t even go to the pictures or on a family holiday. And then there’s the damage she’s done to the house. She put her bare foot through her bedroom door.’’

Manning says the violence that can
accompany autism is unremitting.

‘‘Sometimes they are out to hurt you and they don’t mean to. My daughter had me on the ground [and was] out to kill me without even realising it. The bigger boys get you and pin you down and they wouldn’t hesitate strangling you to death. It is full on. People don’t realise,’’ she says. ‘‘She’ll cut her finger with a knife. She feels no pain. She will take off and run around naked but the way her body is changing -- she’s a woman now.’’

Autistic children never grow up in a mental sense. Few marry or have relationships and parents often have their children for life.

‘‘Belinda is in school till she is 20 but after that I will have to give up work and be stuck at home with [her]. That breaks my heart.’’

Depression, says Manning, is almost par for the course. ‘‘It’s easy to get depressed. It’s so hard to fight it. I hide mine pretty well.’’

Part of Manning’s depression comes from knowing the family has had to sacrifice so much -- including being forced overseas to the US to get an adequate diagnosis for Belinda -- and yet is receiving so little.

‘‘We’re not wealthy people but money is not an issue. I would go without or sell my car just to give her proper medical treatment. We truly love our daughter and I’d give up anything for her,’’ she says. ‘‘But no one wants to know about her and we have to pay for so much out of our own pocket.’’

President of Carers NSW Louise Gilmore estimates the nearly one million carers in NSW only pocket $5 a year each from the Government’s Care for Carers program.

‘‘It’s really a drop in the bucket. We want to try to increase this 300 per cent to $15 million a year,’’ she says. ‘‘That is one practical thing. The Government needs to start looking at this as an investment. These carers are an investment, not a burden.’’

The majority of care is delivered by unpaid family and friends and only 9 per cent delivered by the home and community care service.

Suzan Reid has found the door closed when she has tried to get respite from Brodie.

‘‘I went to DOCS and I said ‘if you don’t help me I’ll leave him here. I really need respite and to this day I got one weekend since April.’ It’s just not enough,” she says.

President of Action for Autism and the father of autistic son Kieran, Bob Buckley, says the system for dealing with autism is nearly non-existent.

‘‘Kieran not only has autism but he also has a disabling heart condition so I’m able to compare what happens to children in terms of services for pediatric cardiology with children with autism,” he says.

‘‘There’s a whole process that comes into play when you have cancer or a heart condition or mental health but that doesn’t exist for autism. I don’t know of any government agency that provides a discernible level of appropriate therapy for children with autism in Australia.”

Minister for Community Services Carmel Tebbutt says she knows more needs to be done.

‘‘I accept that we need to continue to do more and we will continue to do more. We have announced more money for respite,” she says. ‘‘But I have to say that it also takes time to grow the capacity in the services. It takes time to set up new services and we will continue to do what we can to better support parents and carers of a child or young person with a disability.”

Louise Gilmore says many carers hear the words but cannot see any change in their lives.

‘‘Another budget, another lot of promises and our lives are not changing. There’s that level of desperation that is rising,” she says.

Life of fear and chaos

Autism reveals itself by unusual behaviours

Autism results from a severe dysfunction of the central nervous system and affects the way a person processes information. This means the way they understand the world and the way they relate to other people and what is happening around them is often chaotic and frightening.

Autism reveals itself in sufferers as repetitive and restricted behaviours and interests.

There are three autism spectrum disorders. They are autistic disorder (commonly known as childhood autism), Asperger’s disorder and Atypical autism.

All autism spectrum disorders are characterised by repetitive and restricted behaviours and interests, social interaction disability, and communication impairments. These are commonly referred to as the Triad of Impairments.

There is strong evidence of a biological/neurological basis for autism. However, there is no single known cause. As yet there are no medical tests that can be used to diagnose it. Instead, doctors and psychologists look for the presence of particular behaviours.

These may include impaired communication; difficulties in interpreting and using gestures, facial expression and vocal tone; repetition of heard phrases and words and lack of comprehension of words; severely impaired social skills, including difficulties maintaining eye contact and conversations and very specific and unusual preoccupations and attachments.

People with autism often experience overwhelming anxiety, frustration and confusion when faced with the demands of everyday life.

It is a lifelong disability. However, with intervention and support, the condition may improve greatly.

* SOURCE: www.autismnsw.com.au. Reproduced with the permission of Autism NSW.

The Daily Telegraph, Edition 1 - State SAT 16 AUG 2003, Page 026

Raising Harrison has been our toughest job

By: *Judy Brewer Fischer*

The wife of former deputy prime minister Tim Fischer has been on a rollercoaster ride of emotions since their son was diagnosed with autism

When I read of the tragedy that has engulfed the Dawes family this week, like so many of your readers, I was overcome with emotion.

I wanted to find this grieving mother, hug her and tell her I will fight for her, to somehow show her that I understand just a fraction of what she and her husband and daughter must be suffering. To let her know that we in the carers community understand that there are times when it all seems too hard.

Moments when the physical, emotional and financial stresses become overwhelming. When the combination of years of tiredness and fighting for resources, the pressure on your relationships and the juggling of the needs of other siblings becomes a mountain too big to climb. I do not condone what has happened but I do share some of the responsibility in being part of an Australian culture that has let this family down.

In the seven years since our son was diagnosed with autism I have met many families living with unreasonable stress. Parents who have given up careers to be carers; parents who work multiple jobs to raise money for treatments; parents who train as teachers or therapists so they can work out what to do for their child; parents who read all night to become experts in autism to help their child when no one else will.

I ask you to put yourself in the shoes of these families and to think how they would deal with this situation. Your beautiful child is constantly unhappy and difficult to deal with. Your friends, relatives and various professionals suggest maybe it is your fault -- you are not strict enough and your child is spoilt or just not getting the right social environment to develop normally.

Finally, a professional, perhaps on visit number 20, tells you that it is not your parenting skills that are lacking, your child in fact has autism spectrum disorder.

You don't know whether to laugh or cry. For many people it is initially a relief or an answer to the many questions and self doubts but it is not long before you realise the impact of what you have been told.

You will be the primary carer of a person who has a lifelong disability, for which there is no accepted cause and no known cure.

It is a medical condition but not recognised as such and so the treatment is not supported by the health system. It is acknowledged that intensive early intervention is imperative but the waiting lists are often longer than the age bracket for which they are appropriate.

In essence, you are out there alone, living with a child or adult with extreme needs and in many cases receiving NO support. In these circumstances it is very hard to be optimistic and positive about your family's future, and to find the energy to keep fighting.

However the good news is that with the right interventions and with appropriate support, children with autism make extraordinary progress. We have seen this first hand with our son Harrison. It has

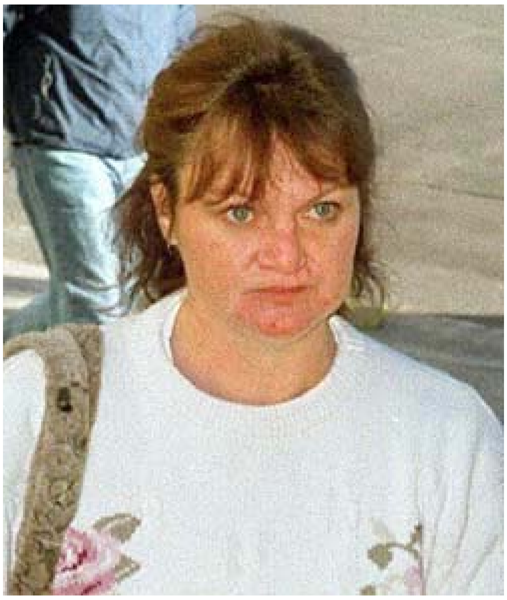
taken a lot of adjustments but we have been blessed in finding special people along our journey that have helped him learn and cope with the anxiety and the extra demands he faces all day, every day.
With the help of a supportive school environment and a caring rural community, we have exceeded many of our earlier expectations. I do not for a moment pretend it has been easy. It has been the hardest years of our lives.
How much harder must it have been for the Dawes family. My heart bleeds for them.

* Judy Brewer Fischer wrote this article following a request from The Daily Telegraph.

From: Melissa
Comment: I am sorry to hear the Daniela is in such a horrible position, but it comes down to the fact that she suffocated her own son and that itself is crime beyond anything. Whether her son was sick or not that has nothing to do with it at all. He has just has much a right to be in this life then anyone else here. So people should understand she commited a crime and now she must pay the price just like everyone else.

Mum cries for Daniela

By VANESSA McCAUSLAND
19aug03


Janine Albury Thompson.

WHEN a New Zealand mother who killed her autistic daughter heard about the allegation against Daniela Dawes, she put her head in her hands and cried.

Janine Albury Thomson, who inspired a New Zealand government inquiry into autism, immediately sent a message of support to Mrs Dawes.

Mrs Albury Thomson was charged with 17-year-old Casey's strangulation murder five years ago. Daniela Dawes was charged with suffocating her 10-year-old son Jason two weeks ago.

"I feel like I know Daniela very well even though I've never met her," Mrs Albury Thomson said.

Mrs Albury Thomson, whose manslaughter sentence was reduced to 18 months from four years on appeal, gave some insight into what forced her to kill the child she loved.

"It was love and desperation – I was on mental, physical and emotional overload," she said.

She spoke of the lack of understanding her daughter Casey received from the community in the last year of her life.

"People only saw Casey's faults, so I'm angry about that.

"Autism is a gift. But it's one of the loneliest ones you can ever have. I want to tell people not to be afraid of it," she said.

Mrs Albury Thomson's case inspired such public empathy that her sentence was reduced.

"I only served one year because the public didn't want me to be in prison. But what happened with my daughter and myself, I will never accept it," she said.

Daniela Dawes' close friend Kris Cook said she had been reading *The Daily Telegraph's* letters of empathy in prison.

"She's absolutely overwhelmed by it," Ms Cook said.

Mrs Albury Thomson said Mrs Dawes had a long, hard road ahead of her, regardless of the outcome of court proceedings, and that she was praying for her.

She said for the rest of her life she was going to be that lady who killed her daughter.

Heartbreaking scenes from a family album

20aug03

CRAIG Dawes walked into Long Bay Jail with his little girl Alana at the weekend to visit the woman they both dearly love.

They made their way past armed guards, barbed wire and a mind-numbing fear -- they walked on in love and hope and dedication to one another.

"We walked through prison gates and past bars to get there," explained a drained but determined Mr Dawes yesterday.

"There are SWAT teams walking around. You go in and it's a stainless steel toilet and a bed. Even I'm scared and I know I'm coming out of there."

It was the first time Daniela Dawes has seen her 13-year-old daughter Alana since the funeral of her brother and Daniela's son Jason a week ago.

"It was total emotions and 'I love you, I love you'," Mr Dawes said. "It took a good five minutes to calm down and then we were able to sit at a table and cuddle and talk. They are allowing us to show our love and feelings."

Mrs Dawes is charged with the suffocation murder of her 10-year-old autistic son in her Kings Langley home.

The cold, hard prison cell is two weeks and a lifetime away from the close-knit family-of-four's suburban life together.

But Craig Dawes entered the prison cell, which houses a woman who has been charged with the unthinkable act of killing their child and told her he loved her.

"I love Daniela," he said yesterday.

"I spoke to Daniela and I said I have a four-bedroom unit for us. She wondered why it was so big and I said one room for Alana, one for guests and I said one for you one day honey."

Craig Dawes' unconditional love is a testament to the unswerving dedication of childhood sweethearts. The two, now aged 38, met at high school when they were 18 and married at 21.

"I worked out the other day that we've spent only 20 nights apart from each other in all those years," he said.

For a family with an autistic child, such a relationship is almost unheard of.

The Dawes ran a milk bar in Ballina for 10 years, surrounded by a group of friends who all shared their situation.

"We had a core group of about 10 families who all had disabled or high-need support kids," Mr Dawes said.

He and Daniela are one of just two couples that are still together.

"Having an autistic child destroys marriages," Mr Dawes said.

"Eight of that group of 10 are now separated. You just can't have a normal marriage."

The couple had to leave their support group and their home to seek help for their beloved child Jason in the city.

"We moved to Sydney intending to get respite," he said.

"The stuff we had up there in Ballina was minimal. The people that co-ordinated respite said 'mate, good decision. You get to Sydney and you're going to get all this set up' and we thought 'OK, we have to go'. We left a beautiful home. We came down."

Their story is a too familiar one.

"We concentrated on re-establishing our lives and we found ’oh no, we’ve got no respite care now’. We had more respite in Ballina, which in itself was minimal.

"People told us, because it’s such a big city, there was a lot more money for respite."

The reality was different.

"When we got to Sydney 2 1/2 years ago they said ’sorry mate, up there you’re a big fish in a little pond, down here you’re just a little fish in a big pond’."

Without in-home respite care, the family struggled.

Mr Dawes eventually found work as a greenkeeper and Daniela Dawes worked as an office clerk part-time, spending the rest of her time caring for Jason.

"Daniela was on anti-depressants for so long," Mr Dawes said. "I’ve been on them myself through the years."

"Depression came to our house when autism came to our house. The issue is in-house respite care. You can’t take autistic children outside the house for care."

Friends of the Dawes talk of Jason’s sister Alana as a 30-year-old in the body of a 13-year-old. She helped bathe and look after her energetic little brother.

"He was always smiling and bubbly," Alana said.

Ian Roberts, the principal of Kings Langley Primary School, one of the numerous schools Jason attended in the last three years, remembers Jason as a great little boy.

"I can recall times when I was there sitting on the floor with him counting things or pointing things out or getting him to spell things on his spell board," he said.

"He certainly did show us emotion. I can remember his smile. I can remember him playing little hand clapping games with the other children from time to time.

"His teacher’s aides use to sit and sing to him. He loved music and would just be caught up in that sort of thing. He had some enjoyment and pleasure in what he did.

"We were very concerned to make sure his life skills were enhanced."

Stories of Jason’s talent with electronics and computers and his endless fascination with reading telephone books filter thorough the family’s grief.

Mr Dawes has spent endless hours of his own grieving process reading the hundreds of letters from people describing their own experience of raising a child with autism.

"There’s a letter there from a woman who has an autistic child. She feels so guilty that she didn’t come and help us," he said.

"She doesn't even know us. We've never met her but she is feeling guilty she wasn't there for us. Some people that we don't even know feel guilty that they've let us down. The letters have been beautiful.

"One lady wrote and said she was considering killing her autistic child and herself but that things have changed after reading about our situation.

"Another woman said she was battling depression and after hearing our story went out that day and got on anti-depressants."

Mr Dawes looks fragile as he talks of support from a community showing empathy and demanding a tragic failure of the system be recognised and changed.

Mr Dawes read the story of Janine Albury Thomson, the New Zealand woman who killed her autistic daughter Casey.

The New Zealand Government called an inquiry that changed autism care and services in the country.

"That makes me feel like that is what should happen with Daniela," Mr Dawes said. "The community should understand -- the community does understand."

From: Jennifer
Comment: Where is the concern and sympathy for Jason? How can everyone be so concerned about care for his mother, who murdered him, when he was subjected to such horrible behavior simply because he was "difficult?" What are we coming to?

High cost for a priceless son

By ZOE TAYLOR Medical Reporter
21aug03

WHEN Finley Harris was first diagnosed with autism at two years old, his parents were told: "Go home and mourn the loss of your son."

Finley could not communicate, his parents and brothers' faces were covered with scratches and bruises from him lashing out and they were told nothing could be done.

"They couldn't tell us what programs we could use or what help there was out there for us," said mum Robyn.

Finley Harris with mum Robyn yesterday.

"We were just told to report to the Autism Association of NSW. For anything that was available, there was a waiting list."

Seeing Finley, now 10, playing with his puppy in the back garden of his Kensington home, it is hard to believe he is the same boy his parents were told was a lost cause.

He can read, play and be reasoned with, but it has been a marathon journey for the family and has cost tens of thousands of dollars.

With three other families, the Harrises flew over a specialist from America to train psychiatry students in a technique now known as applied behaviour analysis. For two years Finley had one-on-one therapy at home at a cost of about $30,000 a year.

By the time he was five he was able to cope at a mainstream school, with a classroom assistant.

His family receives $78 a fortnight in disability allowance and gets five hours of respite care every fortnight. They were on a waiting list for five years for the respite care.

The lack of support for autistic children has been highlighted by the case of Daniela Dawes, who has been charged with murdering her 10-year-old son Jason in their Kings Langley home.

"When I heard about the Daniela Dawes case, it just broke my heart," Mrs Harris said.

She has set up a charity and plans to open a school for autistic children in Sydney next year.

There are an estimated 15,000 children affected by the autism spectrum of diseases in NSW.

The Autism Association, which receives $12 million of its $15 million income from Federal and state government funding, has six schools providing just 340 places.

A further 400 children are on the association’s waiting list.

"Every family should be given this opportunity. Not all children respond as well as Fin, but they should be given the chance to learn and the chance of happiness," Mrs Harris said.

Research has shown that almost half the autistic children treated with ABA can enter mainstream school and are indistinguishable from their peers.

Mother kept behind bars

By LISA MILLER

23aug03

THE family of Daniela Dawes yesterday sat through more than two hours of a bail hearing hoping she would be freed from Long Bay and reunited with her loved ones.

They now face an agonising wait over the weekend after a magistrate said he needed more time and "concrete evidence" before deciding whether to release Mrs Dawes into the care of her family.

Mrs Dawes, 38, is on remand in the jail hospital, charged with murdering her 10-year-old son Jason at their Kings Langley home on August 4.

She is receiving medical treatment after she allegedly attempted suicide after Jason died, and is also on medication for depression.

The adjournment clearly disappointed her husband Craig and the family.

"We just have to wait till Monday, I guess. I'm anxious for Monday," he said. "We're coping OK – we're all still on the mission. I wasn't shocked, I think the judge is just making sure she is being kept in a secure environment."

During the bail hearing at Penrith Local Court, her barrister Nancy Mikhaiel outlined a comprehensive plan drawn up by Mr Dawes and other family members to ensure she would be properly supervised if eventually released from prison.

It included staying with relatives in Liverpool, who would remain by her side 24 hours a day, as well as arranging psychiatric counselling.

Prosecutor Peter Wood opposed bail, citing concerns for Mrs Dawes' mental health as well as the welfare of her 13-year-old daughter Alana, who is currently in the care of her father.

"Without constant supervision . . . she is at risk of further self-harm," Mr Woods told the court.

He said Mrs Dawes would receive better psychiatric care in custody than on bail.

But Ms Mikhaiel said her client would be released from Long Bay jail in one week, and would then be transferred to Mulawa correctional centre.

If moved to Mulawa, her family would hold "grave concerns for her safety, arising out of the nature of the offence she's alleged to have committed," she said.

"She can receive better care in the community than she can in jail."

Mrs Dawes was no longer a suicide threat and also posed no danger to her daughter or to the broader community, Ms Mikhaiel said.

While there was no presumption in favour of bail, "people get bail for murder all the time," she said.

Magistrate Paul Sloane said he needed to see evidence of doctors' appointments and referrals to psychiatric specialists before making a decision. "This is a serious matter, a tragic matter," he said.

"I feel I should have further information before me."

Mrs Dawes sat quietly in the dock as her fate was being decided, occasionally exchanging glances with her husband, who sat just metres away.

As she was led out of the dock he signalled that he would phone her, mouthing the words "it will be OK" before leaving the courtroom.

She must now wait until 9.30am on Monday before learning whether she will remain imprisoned until her case comes to trial.

The Daily Telegraph, Edition 1 - State TUE 26 AUG 2003, Page 007

Free at last: mother on murder charge wins bail

By: LISA MILLER

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.

Daniela Dawes was released into the care of family members late yesterday afternoon after Penrith magistrate Paul Sloane found she posed no threat to community safety.

Last night, her husband Craig and 13-year-old daughter Alana visited Dawes at her relative's home, where she must remain under 24-hour care until the allegations against her are brought to trial.

Mr Sloane also ruled Dawes must receive appropriate psychiatric care and counselling, and must report to police three times a week.

She was released exactly three weeks after her 10-year-old son Jason died of suffocation in the family's Kings Langley home.

She later allegedly told police she was suffering from depression at the time of his death.

The bail hearing was adjourned after a two-hour hearing last Friday, but yesterday Mr Sloane took less than 20 minutes to announce his ruling.

Flanked by members of both his and his wife's family, Mr Dawes punched his fist in the air in relief as the decision was handed down.

Outside court he told The Daily Telegraph his wife would receive better medical and psychiatric care in the community than she would in jail.

“We're happy she's getting the care she needs. Her family can provide adequate security and the magistrate has recognised this,” he said. “We all know she has a mental condition which needs to be treated, and that will be improved by being surrounded by family and friends.”

Mr Dawes immediately rang his daughter to pass on the good news. “She's been pining for her mother,” he said.

“She's very mature for her age, she understands the gravity of the situation and she knows she can help just by visiting her mum.”

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.

Caption: Relief ... Craig Dawes yesterday Finally with her family ... Daniela Dawes who was released on bail yesterday with her autistic son, Jason, who she is accused of murdering. Illus: Photo

Health: Autism
(Question No. 1992)

Senator Allison asked the Minister for Health and Ageing, upon notice, on 11 September 2003:

> **From Senate Hansard, Wednesday 29 October 2003 (http://www.aph.gov.au/hansard/senate/dailys/ds291003.pdf) , page 16680.**
> ***Senator Ian Campbell****—The Minister for Health and Ageing has provided the following answer to the honourable senator's question:*

(1) How many children in Australia were diagnosed formally with autistic disorder in each of the years 1983 to 2002 by: (a) age group; and (b) 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: (a) age group; and (b) 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: (a) age group; and (b) state and territory.

> *(1) (a) and (b), (2) (a) and (b), (3) (a) and (b) There is no national data on the diagnostic profiles of people with autistic disorder and/or Asperger's syndrome and/or pervasive developmental disorders. However, some States and Territories may keep their own records. Various health professionals eg General Practitioners, psychiatrists, paediatricians, psychologists are involved in the diagnosis of these disorders and there is no law which requires them to report their diagnoses, and there is no registry of people diagnosed with these conditions. Therefore it is not possible to say how many are diagnosed with these conditions each year. Some conditions eg cancer, do have central registries but that is not the case with this group of conditions.*

(4) (a) Can an explanation be provided for the disparity in Australian Institute of Health and Welfare data from 1998 that shows adult rates of autism spectrum disorder to be significantly lower than those for children, given that this is a lifelong condition; and (b) to what extent can the disparity be attributed to better diagnosis.

> *(4) (a) The Australian Institute of Health and Welfare data that is referred to are data from the Australian Bureau of Statistics 1998 Survey of Disability, Ageing and Carers. This is a point prevalence survey based on self-report data. (b) I am unable to comment on this question. The modelling by the Institute, which gave an estimate of 29,730 with Autism Spectrum Disorder in 1996, did assume that people who were diagnosed as children continued to have Autism Spectrum Disorder as adults. That is why the 29,730 is higher than the 12,985 reported in the 1998 Australian Bureau of Statistics Disability, Ageing and Carers Survey. Of the 12,985, 11,339 were children 0-14 years, and no one aged 45 or over reported an autism-related disorder.*

(5) Does the Government agree with recent comments by Professor Fiona Stanley that there is an epidemic of autism; if so, what is the extent of the epidemic.

> *(5) We have no evidence by which to assess this. Autism is seen as a range of developmental disorders that are neurobiological and significantly impact on child development.*

(6) With reference to the December 2002 report of the Employment, Workplace Relations and Education References Committee, 'Education of students with disabilities', which 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.

> *(6) The Government has taken no specific action in relation to children with autism or Autism Spectrum Disorders. The provision of treatment is the responsibility of the treating clinician.*

(7) What are the assumptions that underlie the fact that in Australian Bureau of Statistics statistics, children with autism are grouped with those with intellectual disability.

> *(7) The number of children with autism is collected in the ABS Survey of Disability, Ageing and Carers (SDAC). The coding of the conditions reported in this survey follows the International Classification of Disease (ICD10) guidelines, which describes autism as: 'a type of pervasive developmental disorder', under the broader category of 'Mental and behavioural disorders'. The International Classification of Disease (ICD10) is developed by the World Health Organisation with Australia's input to development managed by the Australian Institute of Health and Welfare.*

(8) Is the Government aware that a survey of paediatricians in Victoria in 2002 identified autism as one of the more difficult areas of practice.

> *(8) As the Australian Government was not involved with the survey of paediatricians in Victoria, I am unable to comment on the findings.*

(9) What measures has the Government adopted for ensuring that children with autism spectrum disorders receive effective, evidence-based treatment for their condition.

> *(9) Autism is regarded as a neurodevelopmental disease. Therefore the provision of services is usually addressed through State and Territory disability programs and I cannot comment specifically on this question. The clinician is responsible for the treatment of the condition.*

(10) Is the Government aware that the Medical Journal of Australia editorial, 2003, 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'.

> *(10) Yes. However, the provision of services for developmental disorders are usually addressed through State and Territory disability programs.*

(11) What efforts have been made by the Commonwealth to see that: (a) health professionals are adequately informed in the diagnoses 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; and (c) all children with autism spectrum disorders can readily access appropriate early intervention and treatment such as speech therapy, occupational therapy and physiotherapy.

> *(11) (a), (b) and (c) The provision of health and disability support services is a responsibility of each State and Territory.*

(12) With reference to the establishment by the United Kingdom Government of specialist research institutes for autism spectrum disorders, has the Government considered doing so in Australia; if not, why not.

> *(12) No. The Australian Government has a single research funding agency, the National Health and Medical Research Council (NHMRC), which supports research across the entire health and medical continuum.*

(13) (a) What research is currently underway; and (b) what is planned in the future looking into the cause, diagnosis and/or treatment of autism spectrum disorders in Australia.

(13) (a) The NHMRC is currently funding seven grants relevant to Autism Spectrum Disorders, with a 2003 budget of approximately $717,500. In addition, the NHMRC will provide approximately $31 million in 2003 for funding other research projects into mental health and neurosciences, which may have the potential to benefit those suffering from a range of conditions including autism; and (b) The NHMRC funds health and medical research across a wide range of disciplines, mainly on the basis of excellence, significance of achievement, approach and feasibility of the proposed research, and on the record of the applicants, as judged by a rigorous system of peer review. As a general rule, the NHMRC does not direct researchers to undertake research in a particular area, but rather relies on the researchers themselves to determine the topics for investigation.

Health: Autism

(Question No. 2186)

Senator Lundy asked the Minister representing the Minister for Health and Ageing, upon notice, on 7 October 2003:

(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 Revisions (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.

Senator Ian Campbell —The Minister for Health and Ageing has provided the following answer to the honourable senator's question:

(1), (2) and (3), (a), (b) and (c) There are no national data on the diagnostic profiles of people with autistic disorder, Asperger's syndrome and pervasive developmental disorders/autism spectrum disorders (ASD). Autism is one of a number of intellectual and developmental disorders that are clustered together under the International Classification of Disease (ICD10) guidelines which describe autism as 'a type of pervasive developmental disorder'.

Autism Spectrum Disorders are a general classification within the group of Pervasive Developmental Disorders and encompass a range of subtypes of autism (Asperger's Disorder and Autistic Disorder) with varying degrees of severity. In general, Autism Spectrum Disorders are a group of disorders that have in common lifelong developmental disability. The disorders are thought to be caused by dysfunction in parts of the central nervous system that affects the way the individual processes information. There is no cure for the disorders though changes in ability and behaviour occur over time, and some individuals show remarkable improvement throughout their lives.

The Australian Bureau of Statistics does not separately identify data on autism. Autism is not a reportable medical condition and the numbers of autistic children identified in the 1998 Survey of Disability, Ageing and Carers is self reported and are relatively small and subject to sampling error.

Autism is a disability condition with disability services being primarily the responsibility of the Department of Family and Community Services.

(4) (a), (b) and (c) We have no evidence by which to assess this.

(5) We have no evidence by which to assess whether a similar situation exists in Australia.

(6), (7), (8) (a) and (b) and (9) As stated in Questions 1, 2 and 3 above, there are no national data on the diagnostic profiles of people with autistic disorder and/or Asperger's syndrome and/or pervasive developmental disorders.

(10) The provision of treatment is the responsibility of the treating clinician. Therefore, I cannot specifically comment on this question.

Health: Pervasive Development Disorders

(Question No. 2663)

Mr Byrne asked the Minister for Health and Ageing, upon notice, on 23 October 2003:

(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.

Mr Abbott —The answer to the honourable member's question is as follows:

(1) This is the most common diagnostic system used in mental health services in Australia.
(2) (a) As the Australian Government does not provide services in relation to the diagnosis of children with autism, I am unaware of how services have changed for people with autism to reflect the clinical nature of autism. (b) The provision of treatment is the responsibility of the treating clinician, and may cover educational programs focusing on improving communication, social, academic, behavioural and daily living skills.
(3) No. There are no national data on the diagnostic profiles of people with autistic disorders. The provision of services in relation to autism is addressed by individual State and Territory disability programs with the provision of treatment the responsibility of the treating clinician.
(4) (a) The National Health and Medical Research Council is currently funding seven grants relevant to autism spectrum disorders, with a 2003 budget of approximately $717,500. In addition, the National Health and Medical Research Council will provide approximately $31 million in 2003 for funding other research projects into mental health and neurosciences, which may have the potential to benefit those suffering from a range of intellectual and developmental disabilities. (b) No. As mentioned above, the provision of services in relation to autism and mental health are addressed by individual State and Territory Governments. The provision of treatment is the responsibility of the treating clinician

Health: Autism
(Question No. 2559)

Ms Ellis asked the Minister for Health and Ageing, upon notice, on 8 October 2003:

(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 and 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.

Mr Abbott—The answer to the honourable member's question is as follows:

(1) and (2) There is no national data on waiting lists of people with autistic disorder and/or Asperger's syndrome and/or pervasive developmental disorders.

(3) The estimates by the Australian Institute of Health and Welfare of the prevalence of Autism Spectrum Disorder in 1996 (AIHW : Mathers et al 1999) were based on overseas studies. By applying an average of overseas prevalence rates to the Australian population, it was estimated that the prevalence of autism spectrum disorder in 1996 was 29,730 with about 528 new cases per year. This is an incidence rate of 0.66 for 0 to 4 year old boys per 1,000 population and 0.14 per 1,000 for 0-4 year old girls.

(4) These estimates will be revised in 2004, and will take into account recent Australian studies and data.

(5) (a) and (b), (i) and (ii) National Health and Medical Research Council funding for research related to autism in 2003 will be $717,512. This is approximately 0.3% of the total National Health and Medical Research Council funding for new and continuing grants in 2003.

In addition, the National Health and Medical Research Council will provide approximately $31 million in 2003 for funding of research projects into mental health and neurosciences, which may have the potential to benefit those suffering from a range of conditions including autism.

Information relating to funding in 2004 is not yet available.

(6) (a) and (b), (i) and (ii) The Australian Research Council does not fund research in the area of clinical medical research.

However, in its area of responsibility the Australian Research Council has provided $241,360, between 1999-2004, for socially based autism/ASD related projects.

(7) I am unaware of any other funding programs or projects being conducted specifically outside the work of the National Health and Medical Research Council and the Australian Research Council.

(8) The National Health and Medical Research Council funds health and medical research across a wide range of mental health and neuroscience disciplines which may include autism.

I am unable to comment on the funding arrangements of other organisations.

(9) (10), (11) and (12) The comparison cannot be made because there is no national data on the diagnostic profiles of people with autism/ASD.

Health: Autism
(Question No. 2657)

Ms Gillard asked the Minister for Health and Ageing, upon notice, on 16 October 2003:
(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.

Mr Abbott—The answer to the honourable member's question is as follows:

(1) (a), (b) and (c) and (2) There are no Australian or internationally agreed figures for people with autistic disorder, Asperger's Syndrome, pervasive developmental disorders or autism spectrum and related disorders.

(3) (a) and (b) The Australian Government does not provide services in relation to the diagnosis of children with autism and related disorders or Asperger's Syndrome. This is a state and territory responsibility and the provision of treatment is the responsibility of the treating clinician. The Australian Government does not collect data on availability of services or on waiting lists.

(4) and (5), (a) and (b) It is well recognised clinically that autism and Asperger's Syndrome can be very difficult to diagnose with the spectrum of Pervasive Developmental Disorders. There is no information of which I am aware that has formally assessed the accuracy of diagnosis in Australia.

(6) There is increasing evidence that behavioural intervention may improve cognitive, communication, adaptive and social skills in young children with autism. However this is by no means accepted in mainstream approaches to clinical care.

The Australian Government does not provide any policy, coordinating or monitoring role in relation to these services.

(7) (a), (b), (c), (d), (e), (f) and (g) As stated in Questions 1 and 2 above, there are no national data on the diagnostic profiles of people with autistic disorder, Asperger's Syndrome, pervasive developmental disorders or autism spectrum and related disorders.

(8) The AIHW in its 2003 publication, "Disability support services 2002 – National data on services provided under the Commonwealth/State Disability Agreement", includes data on service consumers with autism reported as the primary condition.

There were 2,500 service consumers recorded with autism as the primary condition on the snapshot data collection day (3.8% of consumers), and 73% were aged under 25 years. Only 301 (12%) were accessing employment services, and of the 1,276 consumers aged 16 years or more only 42 (3%) reported paid employment as their main income source. Some 89% reported the Disability Support Pension as the main income source.

(9) There is no specific review underway. The National Health and Medical Research Council will provide approximately $31 million in 2003 for funding research projects into mental health and neurosciences, which may have the potential to benefit those suffering from a range of intellectual and developmental disabilities.

2397 **Senator Allison:** To ask the Minister representing the Minister for Health and Ageing—With reference to the answer to question on notice no. 1992 (Senate *Hansard*, 29 October 2003, p.16679)

(1) Does the Government plan to establish central registers for: (a) autism; (b) Asperger's syndrome; and (c) pervasive developmental disorders; if so, when; if not, how will the Government ensure that there is sufficient attention available from treating clinicians in Australia for the people with these conditions.

(2) Which states and territories keep data on the number of people with: (a) autism; (b) Asperger's syndrome; and (c) pervasive developmental disorders.

(3) Do any state registers show increasing diagnoses of autism spectrum disorders (ASD).

(4) (a) What is the extent of changes in diagnosis rates; (b) is there a consistent pattern in the available data; and (c) is the pattern similar to recent reports from overseas.

(5) Is the Government aware that: (a) the Western Australia 'Register for Autism Spectrum Disorders 2001' report states that there were 159, 173 and 204 ASD diagnoses in 1999, 2000 and 2001 respectively; and (b) the figure of 204 diagnoses in 2001 corresponds to 0.77 per cent of the birth rate in Western Australia.

(6) Is the Government aware that: (a) data from the Australian Capital Territory shows that the number of ASD diagnoses in 1989 and 1997 were 17 and 45 respectively; and (b) the figure of 45 ASD diagnoses in 1997 corresponds to 1 per cent of the birth rate in Australian Capital Territory.

(7) Are the diagnosis rates observed in Western Australia and the Australian Capital Territory much higher than the estimate used by the Australian Institute of Health and Welfare (AIHW) in its 1999 report on the 'Burden of disease and injury'.

(8) What is the basis for the department's claim that autism affects only 2.5 Australians per 10 000.

(9) Given that the Government described the Australian Bureau of Statistics (ABS) Survey of Disability, Ageing and Carers as 'a point prevalence survey based on self-report data': is there a problem with a survey such as this, that shows 'adult rates of autism spectrum disorder to be significantly lower than those for children'; if so, what is being done to ensure that quality data describing disability and ASD is available to government policy and decision-makers.

(10) Is it possible that the ABS's survey, which uses computer assisted telephone interviews with self-reporting for adults, could under-report adults with autism, since these are people whose diagnosis requires abnormal functioning (usually dysfunctional) in the areas of communication and social skills.

(11) Given that data from the ABS survey shows that autism affected approximately 11 339 children aged 0 to 14 years in 1998, and that there are around 3.9 million children in this age range, does this mean that around 29 children per 10 000 have autism.

(12) Given that data from the ABS survey data shows that autism affects around 1 646 adults aged 15 to 45 years, and that there are around 8.4 million adults in this age range, does this mean around 2 adults per 10 000 have autism.

(13) Does the Government recognise that autism is a lifelong condition.

(14) Does this data suggest that autism is significantly more common in children than in adults.

(15) (a) Which individuals or organisations would be able to comment on the apparent disparity between childhood and adult rates of autism observed in the ABS data; and (b) does the Government intend to consult them.

(16) Does the Government consider that there are no Australians over the age of 45 years with autism or a related disorder; if not, can an explanation be provided for their absence from the survey results.

(17) If the opinion of Professor Fiona Stanley, an esteemed epidemiologist and Australian of the Year, is 'no evidence' of an autism epidemic: does the Government accept that her view at least indicates the possibility that such an epidemic exists.

(18) Will the Government investigate whether Australia is experiencing an epidemic of autism and related disorders.

(19) Which individuals or organisations would the Government regard as suitable to conduct such an investigation.

(20) Given that the Government has stated that it has not acted to ensure that children with ASD can access a treating clinician within the health system, will the Government act to ensure children with ASD can access a treating clinician who will progress them towards their developmental goals.

(21) Given that the Government recognises that autism is not an intellectual disability, will the Government ensure that the ABS, AIHW, the Department of Health and Ageing and the Department of Family and Community Services describe autism and related disorders as being in a distinct category, separate from intellectual disability.

(22) Given that the Government is unable or unwilling to consider research with which it was not involved, will it conduct its own survey of paediatricians to determine whether autism is one of the most difficult areas of practice.

(23) Will the Government's research examine whether paediatricians encounter difficulties because they are unable to refer children with ASD to specialist treating clinicians.

(24) Given that the Medical Journal of Australia editorial, 2003, stated, in relation to autism spectrum disorder that, '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'; and given that state and territory disability programs usually provide the services but that there is no national data on diagnostic profiles: what evidence does the Government have that the states and territories provide the clinical attention required by children with ASD for their effective rehabilitation.

(25) Given that in its response the Government states that it has not considered establishing a specialist research centre for ASD, will the Government consider establishing such a centre in the near future.

(26) Given that important allies such as Britain and the United States of America have responded to increasing rates of autism through targeted services and increased research, does the Government plan to join with a 'Coalition of the Willing' to combat ASD.

(27) Given that the Government states that 'the NHMRC [National Health and Medical Research Council] is currently funding seven grants relevant to Autism Spectrum Disorders, with a 2003 budget of approximately $717,500': can each of these seven grants be identified, including funding and how each of the seven grants is relevant to people with autism.

(28) Given that the NHMRC will provide approximately $31 million in 2003 for funding other research projects into mental health and neurosciences that may have the potential to benefit those suffering from a range of conditions including autism, can details of these grants be provided including the amount of the grant and the potential benefit of each for people with autism.

These questions have not been answered yet.

COMPLAINTS REVIEW EXECUTIVE

Determination of a complaint from Bob Buckley on 19 September 2003

Background

Mr Buckley emailed the producer of ABC Radio National's *The Health Report*, Brigitte Seega, on 6 August 2003 to express concern over commentary provided by the program's presenter, Dr Norman Swan. Two topics were presented and discussed during *The Health Report* on 28 July 2003: 'Callous Unemotional' and 'Food Labelling'.

Mr Buckley, Convenor of Autism Aspergers Advocacy Australia, indicated his offence at comments made during the segment 'Callous Unemotional'. The segment featured a discussion with Professor Mark Dadds from the University of New South Wales School of Psychology. Professor Dadds, at the time, was involved in researching a measurable trait in children called 'callous unemotional'. The transcript of *The Health Report* included:

> **Mark Dadds:** …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.

Mr Buckley indicated that Dr Swan had made unsubstantiated 'utterances' on a number of points:

1. Children are mislabelled autism spectrum disorder
2. People are often mislabelled Aspergers
3. True Aspergers are often quite aggressive people

Dr Norman Swan (both a paediatrician and a broadcaster) responded advising that his intention was not to cause offence or upset and apologised if he had. Dr Swan wrote:

> Concerning the diagnostic dilemma in Autism Spectrum Disorders, there are a few references including an editorial in the *Journal of the American Medical Association::*
>
> Susan L. Hyman, Patricia M. Rodier, and Philip Davidson 'Pervasive Developmental Disorders in Young Children' 2001 *JAMA* 285: 3141-3142
>
> Another two local ones are:
>
> Tonge BJ et al. Autism 1999 *Medical Journal of Australia* 3:117-130 (Which deals with the risk of psychopathy in Asperger's)
>
> Tonge BJ 2002 *Medical Journal of Australia*176:412-413

Mr Buckley emailed Dr Swan on 13 August 2003 asserting that he had not raised an issue of 'diagnostic dilemma' and clarified his complaint:

> My primary concern is that you said "... true Aspergers are often quite aggressive people". This is contrary to my own knowledge and experience. I am unaware of a single authority or expert who supports your assertion.

Mr Buckley indicated that he did not find the references provided by Dr Swan supportive of his understood position. Mr Buckley stated that one of the references provided on the specific subject of Asperger's Syndrome could be interpreted to be '(defensive) violent behaviour rather than aggression' and found that 'violent behaviour is a normal response to anxiety or a perceived threat…This is basic animal instinct…not peculiar to people with Asperger's Syndrome'.

Mr Buckley then asserted that ‘failure to make reasonable adjustment for a person with a disability is often unlawful discrimination’.

Dr Swan replied on 15 August 2003 identifying the reference by Tonge as supportive of his position.

Mr Buckley submitted a formal complaint via comments@your.abc.net.au on 16 August 2003:

> …Dr Norman Swan, in the Health Report on Radio National on Monday 28th July did vilify people with Aspergers Syndrome or Aspergers Disorder. The transcript shows he said true Aspergers are often quite aggressive people.
>
> …Dr Swan has not responded to my specific concerns. All he offers to support his position is a single reference…depending on interpretation sympathetic to his particular view…this is not sufficient basis for his negative characterisation of people with Aspergers Syndrome.

Mr Buckley requested that the ABC correct Dr Swan’s broadcast opinion and subsequent publication on the Internet.

ABC Senior Audience Liaison Manager, Kieran Doyle, wrote to Mr Buckley addressing the issue of misdiagnosis of children with ‘spectrum disorders’:

> …Dr Swan was not giving his personal view as you implied. He had, a few months beforehand, made an ABC television program (Dimensions) on Autism Spectrum Disorder…Moreover, several authors in this field locally and overseas, have raised the issue of over or mis-diagnosis of children with ‘spectrum disorders’.
>
> The reason Dr Swan used the word ‘true’ in his comment about Asperger’s was a belief among some in the field that the label is being used loosely.

In addressing the link of Asperger’s Syndrome with aggression, Kieran Doyle said that the references previously provided by Dr Swan support his comment.

Mr Buckley responded to Kieran Doyle on 16 September 2003 indicating that his primary concern had simply not been addressed:

> It doesn’t matter whether Dr Swan is referring only to people with a clear and undisputed diagnosis of Asperger’s Syndrome ... the claim is not supported by any evidence he or you have cited ... nor by any evidence I am aware of, except in a context of what is likely to be unlawful discrimination.

> …someone in Dr Swan's position should not make unsubstantiated claims that can be especially damaging to a particularly vulnerable part of our community.

ABC Head Audience and Consumer Affairs, Kirstin McLiesh on 16 September 2003 in a response to Mr Buckley suggested that his unresolved issue be referred to the ABC's Complaints Review Executive (CRE). Kirstin McLiesh also provided Mr Buckley with information pertaining to alternative avenues of review available to him in having his complaint resolved.

Mr Buckley expressed his wish for his complaint to be reviewed by the CRE in an email of 19 September 2003 to Kirstin McLiesh:

> Neither Dr Swan nor Mr Doyle have identified any evidence relating to aggression in people with Asperger's syndrome…My complaint is that the ABC presented, and continues to present on its website, the unsubstantiated statement that is unfavourable to people with a diagnosis of Asperger's syndrome.

The CRE undertook an appraisal of Mr Buckley's concerns.

CRE View

Mr Buckley has raised questions about the accuracy of comment in relation to Asperger's syndrome made by Dr Norman Swan while presenting Radio National's *The Health Report* on 28 July 2003.

Dr Swan responded to Mr Buckley's concerns with an apology for any offence caused and provided three references that, he argued, supported his comments. Mr Buckley clarified his complaint in further correspondence with both Dr Swan and ABC Audience and Consumer Affairs.

Mr Buckley has maintained that Dr Norman Swan's comments of 28 July 2003 have 'vilified people with Asperger's Syndrome' and was a 'failure to make reasonable adjustment for a person with a disability is often unlawful discrimination'.

I am not in a position to appraise the views of either Dr Swan or Mr Buckley in what appear to be differing interpretations of published material. I, therefore, commissioned an authoritative third party to assess Mr Buckley's concerns about the specific comment 'They say true Asperger's are often quite aggressive' as stated by Dr Norman Swan on ABC's *The Health Report* 28 July 2003, and Dr Swan's response to those concerns.

The Monash Institute of Health Services Research (MIHSR) was contracted to undertake this independent review. The MIHSR was established in 1999 with the aspiration of being ‘the world’s leading organisation at combining technology and evidence to promote informed, effective and efficient decision making by health care professionals, policy makers and consumers.’

Details of Mr Buckley’s complaint of 6 August 2003 and subsequent correspondence were provided to the MIHSR, without identifying Mr Buckley. Dr Swan’s response was also provided.

Director of the MIHSR, Professor Donald Campbell, undertook this review together with Dr Elmer Villanueva MD ScM, a Senior Research Fellow. The following is a summary of their findings as presented to the Complaints Review Executive:

The MIHSR Review

> The main question of interest was whether there was published evidence that patients with a definitive diagnosis of Asperger’s Syndrome were aggressive.

The methodology employed was outlined as follows:

> This evaluation applied aspects of evidence-based medicine in the search, appraisal, and synthesis of the current best evidence on the topic of interest. It builds on recommendations made by experts in evidence-based mental health concerning the approach…
>
> The primary question is best cast as one dealing with prognosis or aetiology. The issue is recast in this form: “In adults or children with a definitive diagnosis of Asperger’s syndrome, what are the rates of aggressive behaviour (explicitly defined) and how do these rates compare with other populations?” This allows the definition of inclusion criteria and the composition of a search strategy to apply to the published literature conducted using the following databases:
>
> - Ovid Biological Abstracts (1980 to October 2003)
> - Ovid CINAHL (1982 to October Week 5 2003)
> - Ovid EBM Reviews including the Cochrane Database of Systematic Reviews, ACP Journal Club, The Database of Reviews of Effectiveness and the Cochrane Controlled Trials Register (to 2nd Quarter 2003)
> - Ovid Medline (1966 to October Week 5 2003)
> - Ovid PsychINFO (1872 to October Week 5 2003)
> - PubMed (06 November 2003)
>
> …
>
> Full-text articles were retrieved and reviewed for the purpose of applying inclusion criteria were not reviewed. Case-control and longitudinal cohort studies were included, as were series studies, narrative reviews, and

> consensus statements. Textbooks and references on Asperger's Syndrome were consulted as well.
>
> ### *Findings*
>
> **Issues raised in complainant's correspondence of 6 August 2003 referring to ABC Radio National's *The Health Report* broadcast 28 July 2003**
>
> ***(i) Aggression and Asperger's Syndrome***
>
> There was a lack of high-quality evidence to either support or refute the association between Asperger's Syndrome and aggressive behaviour.
>
> Three comparative studies suggest that aggressive tendencies may be present, but the research was often conducted on small groups or on special populations. There was no examination of the extent or severity of these behaviours, nor whether these aggressive behaviours were qualitatively different from general population samples.
>
> Most evidence for or against the association between Asperger's Syndrome and aggression arises from case series, case reports or published clinical opinion.
>
> ***(ii) Diagnostic criteria for Asperger's Syndrome***
>
> The presence of internationally recognised and established diagnostic criteria delineates Asperger's Syndrome as distinct from other forms of pervasive developmental disorders. The presence of closely related conditions makes diagnosis difficult at times.
>
> ***(iii) Vilification***
>
> While the Monash Institute of Health Services Research has no expertise in the interpretation of the law, the legal definition of vilification according to the *Racial and Religious Tolerance Act 2001* (Vic) defines vilification as any form of conduct that incites hatred against, serious contempt for, or revulsion or severe ridicule of another person or class of person on the grounds of their race or religion. Such conduct can be a single event or series of events of a period, and may include the use of internet and e-mail to publish or transmit statements.

The MIHSR review declared the following limitations:

> The information presented in this report represents the best available evidence given the limitations imposed by time, technology and expertise… In the present case, it is inevitable that the entirety of the published information is not captured. However it is unlikely that the pivotal studies are missed given the specific search strategies employed.

> …In this report critical appraisal of the identified information was limited to an assessment of the study design. It is possible that further evaluation will reveal potential sources of bias.

A draft of this determination and the findings of the MIHSR were provided to Dr Norman Swan. Dr Swan's response included the following comment:

> …there is a legitimate debate about the autism spectrum diagnosis of which Asperger's is part. I in fact made a Health Dimensions (ABC TV) on exactly this, where on-air, a developmental paediatrician admitted he adjusted his diagnosis to meet the circumstances of the child and family.
>
> While I bow to MIHSR's expertise in assessing evidence, their comments seem to have one main conceptual problem: they are applying the rigour of randomised controlled trial (RCT) methodology to an area where it isn't relevant. While RCTs don't arise in their comments, I say this because when they use the phrase 'high quality' it's code in the evidence-based community for RCTs when a drug or a test is being assessed. They question case series (see p6) when it's the main way of coming to conclusions about diagnostic criteria. Their criticism that the series were small is correct though.
>
> I think MIHSR's conclusion that you can't decide one way or other from the literature is fair. It's just that the literature and classification systems are serving us poorly when it comes to autism spectrum as indeed they do in Attention Deficit Hyperactivity Disorder.
>
> What I think I was guilty of was not qualifying my remark to Mark Dadds by explaining this issue of aggression in Asperger's was something which was a matter of debate and not conclusive.

CRE conclusion

The MIHSR assessment of *The Health Report* comment that "Aspergers are often quite aggressive people" was that "there was a lack of high-quality evidence to either support or refute the association between Asperger's Syndrome and aggressive behaviour".

On this basis, it appears that Dr Swan may have overstated the connection between the syndrome and aggressive behaviour. It is important to note, however, that Dr Swan's original comment was not in the form of an emphatic observation but rather was indicative of a tendency. The MIHSR assessment suggests that even such a qualified position may be going beyond what is supported by 'high-quality evidence'.

Relying on the MIHSR assessment, Mr Buckley's complaint about the portrayal of a link between the syndrome and aggressive behaviour is upheld.

On the matter of *The Health Report's* vilifying people diagnosed with Asperger's syndrome, what was expressed in the program was a point of view that was genuinely held and not applied universally to all diagnosed with the syndrome. The ABC's *Code of Practice* addresses discrimination in the following way:

> To avoid discrimination programs should not use language or images in a way which is likely to disparage or discriminate against any person or section of the community on account of race, ethnicity, nationality, sex, marital or parental status, age, disability or illness, social or occupational status, sexual preference or any religious, cultural or political belief or activity. The requirement is not intended to prevent the broadcast of material which is factual, or the expression of genuinely-held opinion in a news or current affairs program, or in the legitimate context of a humorous, satirical or dramatic work [2.4].

The complaint about vilification is not upheld.

In relation to medical comments on air, the MIHSR review of Mr Buckley's concerns and Dr Swan's original response, offered the following recommendations:

1. Clear differentiation should be made between **opinion and fact.**
2. In cases where claims are made, it would be useful for **supporting references** to be provided. These might be cited during the broadcast or provided as an additional resource on the ABC Website. For instance, interested listeners might be directed to a list of "further reading". Supporting references should present a balanced exposition of the topic area, especially if controversial.
3. It would be useful for the experts to **acknowledge** the sources of information they provide, especially if these claims are unexpected or controversial to the lay audience. Uncertainty should be acknowledged if it exists. This might be due to the novelty of the information, the presence of debate within scientific circles, lack of evidence, or the presence of equivocal, low-level evidence (as in the present situation).

In response to these MIHSR recommendations, Dr Swan wrote:

> …recommendation 2…*The Health Report* references its material more than any outlet anywhere in the Australian media, print or electronic and we already direct listeners to further areas of interest and have done so for many years. That's one reason we get so many hits on our website: listeners can take things further and make their own minds up. It's just that in this case, what was essentially an indefinite remark as part of a single question in a 30-minute programme, I didn't.
>
> …I would have thought it reasonable to reference the main story being told so the reader can decide for him or herself or follow it up.

I concur with the recommendations provided by the MIHSR, and in doing so understand the complexities raised by Dr Swan.

If there is any dissatisfaction with any aspect of this appraisal then application may be made to the Independent Complaints Review Panel and/or the Australian Broadcasting Authority for further review.

MURRAY GREEN
Complaints Review Executive

17 November 2003