

Challenging and Problem Behaviours in Young Children

By M. Dominguez

Challenging behaviours in young children occur because this is how they learn to participate and make sense of their world. As a parent of a child with Asperger's, with a background in early childhood education, sometimes my child's undesirable behaviours can become overwhelming. I question my abilities as a parent and it seems as though the responsibility is too great. Taking deep breaths, being kind to yourself and being realistic about day to day occurrences can help.

Children do not deliberately display challenging behaviours for the sake of it.

An important thing to remember is that problem behaviours need to be viewed within an ecological context in relation to the environment, the child's developmental level, their ability to communicate needs and wants in a functional manner, and possibilities of what these challenging behaviours can achieve for the child (Richey & Wheeler 2000). Challenging behaviours can also be a child's way of communicating his or her need to "escape, the desire for attention, or a request to a desired object or activity" (Cook, Klein, Tessier & Daley, 2004, p. 223).

Adults need to define clear limits and let children know what is socially appropriate and inappropriate behaviour. Building social competency is paramount so that children can feel valued as an individual. Aggressive children need to know that it is not right to hit or alienate other people. For severe challenging behaviours, access to other professional services who are specialised in behaviour modification may have to be sought.

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Strategies for dealing with day to day undesirable behaviours can include observing and gathering information regarding the purpose of the behaviour to begin with (Kaiser & Rasminsky, 2003) Examine the child's strengths, interest and learning style and focus on these. Always remember to separate the behaviour apart from the child to let them know that it is their behaviour that is causing you to be unhappy and not them. Children need to know that they are loved unconditionally.

Parents / carers can discuss with the centre / school staff regarding their Behaviour Guidance Policy. It is useful to share strategies such as positive behavioural guidance to provide continuity and link practices from home to the child care settings or schools. Importantly, share information in an open manner and be respectful and responsive of each other's point of view.

Specific strategies to use for challenging behaviours can include the ABC analysis which outlines the Antecedent, Behaviour and Consequence method as displayed in Table 1.

Table 1 ABC Analysis

ANTECEDENT	BEHAVIOUR	CONSEQUENCE
<p>What triggered the behaviour?</p> <p>It could be lack of communication skills, hunger, wanting a tangible object or the child acting appropriately according to their developmental age.</p>	<p>What behaviour was displayed?</p> <p>How was it displayed?</p> <p>Environmental cause or trigger?</p>	<p>What happened as a consequence?</p> <p>What could you have done better to alleviate the behaviour?</p> <p>Reflect on:</p> <p>Was the strategy used to deal with the behaviour effective?</p> <p>What would you do differently next time?</p> <p>Could you use other methods eg prevention, redirection, positive reinforcement via praise, positive comments and hugs for good behaviour.</p>

Providing a positive role model to children is crucial. Ferris- Miller (2000) suggests;

- Treat everyone with respect and dignity.
- Really listen.
- Celebrate differences and respect the child's rights.
- Use communication and patience instead of force.
- Respond assertively to misbehaviour and praise positive behaviours.
- Use problem solving strategies to identify the causes of challenging behaviours.
- Give unconditional affection.
- Be consistent

Expression and labelling of feelings need to occur so that children are aware and can learn to differentiate feelings such as happy, sad, angry and so on. Learning that other people have feelings and thoughts is not a built in skill, it is acquired during the individual's developmental progress. Providing means to communicate functionally for children with communication difficulties can prevent frustrations for the child. Provide simple words, phrases or through visual representations in their environment. This can be achieved through

pointing to pictorial representations of their daily needs. Prevention of any power struggle between the adult and child is vital. Through strategies such as being responsive to the child's needs, looking out for triggers of the challenging behaviour, redirection, positive reinforcement using non-tangible objects such as smile, praise and hugs, and teaching children to participate in a socially conducive manner can facilitate successful and positive interactions.

If the challenging behaviour has escalated, it is useful to plan for such events. Within the home or child care centre, the child will need to have a time away place to calm down. This should be a place that has no negative connotation that the child is being punished. This environment should have items such as books or minimal preferred toy / activity. This should provide a message that the child needs a break from others and let them know in a positive manner that they can come and join the group / family when they have calmed down and are ready. This places the onus on the child, depending on the age and special needs, to further develop control of their own behaviour.

The scope of this discussion is limited. There are many websites that deal with challenging behaviours and references will be provided. Lastly, being a parent is not an easy task. We do our best for our children and we can only keep trying.

Keep up the good work and don't forget to give yourselves a pat on the back once in a while and please let the world in!

REFERENCES

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www.csefel.uiuc.edu

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Workshop

Please find attached an advertisement about our Workshop on Asperger's Syndrome and Marriage/Long-Term Relationships with Professor Tony Attwood on 8 July.

We look forward to the possibility of your attendance and would be very grateful if you could also forward this flyer on to other interested individuals or professionals, mailing lists, advertising opportunities, etc.

For further information please see www.assn.org.au

Thanking you.

Carol Grigg
ASPIA INC
0408 817 828

Convenor's message

Dear A4 member

Autism continues to get some attention in the media.

In Sydney, the Daily Telegraph ran a story¹ on May 3 (Help for autism comes at a cost). Most of the story was positive and supportive.

But one of the points was that parents had to spend \$37,000 per year to get an intensive program for their child. The writer then says

No public system could afford to supply such one-on-one treatment.

People often **assume** intensive programs are expensive. But they have never actually examined the costs. A recent ACT Budget reported that the cost of a place in special school is \$40,000 per year. And that cost does not include the specialist input and other disability services provided for a child in special school. The cost of placing a child with autism in a specialist unit in a mainstream school (satellite class or whatever term you prefer) is about \$20,000 per year. Typically, the cost is even lower in a mainstream class.

A program that successfully prepares a child with autism for an Autism Unit in a mainstream school, rather than having children with autism go to special school, saves \$20,000 each year for 12 years, or \$240,000 in total, just in education costs. In other words, it is worth spending \$80,000 per child for early intervention if that early intervention succeeds in getting just 1/3 of its students out of a special school into a school-based autism unit or satellite class (research shows this is an achievable goal).

Generally governments do not recognise that generic special education at \$40,000 per year is a significantly less than optimal service for children with autism. They ignore the fact that ineffective programs are the most expensive of all.

People who say intensive early intervention for autism is expensive just display their profound ignorance, prejudice and economic incompetence.

On the subject of costs, a recently published book² from Harvard University in the USA says autism cost the USA \$35 billion per year. The average cost to care for someone with autism over their lifetime is US\$3.2 million. This is a big increase from the US Senate quick study that suggested ASD cost the US government over \$13 billion per year.

Well you might ask what would this mean in Australia. On the basis that A\$1 in Australia buys the same service as US\$1 in USA, we expect autism/ASD currently costs Australia over \$2.5 billion per year. State and federal governments do not know where they spend this money ... but we can be sure the money is not spent in an ideal manner.

A recent edition of the Health Report on ABC Radio National also focused on autism³. In it, Eric Fombonne, who is often regarded as an international expert in autism/ASD diagnosis rates, says ...

Eric Fombonne: We just reported a rate of .65% which means that about one child in 160 in our communities is affected with an autism spectrum disorder. That's why it has been now reported by at least ten different studies. When I was in the UK I did two studies which confirmed this high estimate.

¹ see <http://www.dailytelegraph.news.com.au/story/0,20281,19002428-5002380,00.html>

² see <http://www.hsph.harvard.edu/press/releases/press04252006.html>

³ you can get the transcript or an MP3 from <http://www.abc.net.au/rn/healthreport/stories/2006/1619796.htm>

This is pretty much the same ASD prevalence as the US Centers for Disease Control and Prevention (CDC) report⁴. And it matches much of the data collected in Australia⁵.

Fombonne suggests the diagnosis rate rose due to a change in US law. However, the diagnosis rate also rose in countries where there was no change in the law, such as Australia. Diagnosis rate started to rise soon after the release of the Rainman movie. Should we blame the increase in autism on Hollywood, Tom Cruise and Dustin Hoffman?

Bureaucrats and some professionals like to say increased diagnosis is due entirely to expanded diagnostic criteria, such as the introduction of Asperger's disorder/syndrome.

The diagnostic criteria have not changed since 1994, and experts said at the time the changes made in 1994 from the DSM-III to the DSM-IV would not change who would be diagnosed. The Asperger's criteria did not "expand" the criteria; it named or distinguished a part of existing Pervasive Developmental Disorders.

To my knowledge, there is no adult population anywhere in the world that has an observed ASD prevalence anything like the levels seen in our children.

It is clear that there was significant under-diagnosis in the past; both for Autistic Disorder and for Autism Spectrum Disorders (or PDDs if you prefer that term). It is not clear that the entire increase in the diagnosis of ASD in children is due to greater awareness and/or better diagnosis. And if better awareness and diagnostic practices explain entirely the increased diagnosis of ASD in children, then our service providers still have an awfully long way to go with diagnosing adults.

Why does this matter so much? Our governments want to believe there has been no real increase in disability due to autism/ASD. That means the existing services, that they claim were wonderful in the past, will continue being wonderful in future. The bureaucrats suggest (and their political masters accept it) there is no unmet need nor any need to change service provisions, and today's parents of children with autism are just a bunch of whingers.

Some bureaucrats even accuse parents, especially mothers, of making their children autistic or more autistic. To me, this seems a worse persecution than the horrific and now discredited accusation of being a "refrigerator mother" thereby causing a child's autism.

I have direct contact with one case where a bureaucrat convinced the family doctor that a mother, who has autism, may have Munchausen's syndrome by Proxy and is making her sons (more?) autistic. I cannot imagine how devastated this mother feels. Nor can I imagine a more ridiculous accusation: I find it hard to imagine how one would make a child autistic (except perhaps by feeding the child with heavy metals); or how a woman with autism would have the social and communication skills to carry off the required deception.

By the way, you will not find Munchausen's syndrome by Proxy in the DSM-IV. There is a Factitious disorder by Proxy in Appendix B. Appendix B lists disorders where there is insufficient information to warrant their inclusion in the DSM-IV. The DSM-IV says "when confronted ... perpetrators may become depressed and suicidal". Remarkably, the DSM-IV does not warn that false accusations can also lead to depression and suicide.

Late in March, I wrote to all the state/territory disability departments and asked them some questions about their understanding of autism and their services. The answers have trickled in recently. I hope to be able to report on what they all say in the next A4 Update.

The Senate Select Committee on Mental Health released its first report⁶ in March and its final report⁷ in April. There is a section on autism in the first report (a couple of pages starting on page 88).

⁴ see http://www.cdc.gov/NCBDDD/autism/asd_common.htm

⁵ see http://autism.anu.edu.au/pdf_files/buckley_submit2.pdf

⁶ http://www.aph.gov.au/senate/committee/mentalhealth_ctte/report/report.pdf (2.4Mb)

There is a new Senate inquiry into the Commonwealth State and Territory Disability Agreement starting up⁸. Please let us know if you have any comments or are interested in helping us develop our submission.

I could not find a single reference to autism or Asperger in the federal budget. If you are lucky, there might be some funding for parent support groups. Good luck accessing it!

Regards
Bob Buckley
Convenor

27/5/2006

Carers call for rolling strikes

After today's passing of the Victorian Disability Bill by the upper house legislation Committee Victorian carers are planning rolling strikes, they will not pick up their family members from respite and day services on chosen days in the coming months, as well as a massive campaign to not vote Labor in the Victorian elections on 25th November.

Opposition parties have been asked to commit to policy that will repeal the draconian sections of this bill.

This bill says that the person with disability (it doesn't matter if they don't have the intellectual capacity to understand it) is the only person to be provided with information. Labor disallowed the inclusion of the person with the disabilities representative in planning, any complaint mechanism or the receipt of any information of any kind pertaining to the care of their sons or daughter who has decision making incapacity.

They refused to acknowledge the carers of the disabled in any way.

As a person with an intellectual disability cannot advocate their own needs, how can they seek any services if the carer cannot represent them?

In other words they can tell an intellectually disabled person that they are being evicted from a group home without informing the family, they can basically do what they want. Against all relevant Federal and other states legislation, Victoria has voted against the inclusion of persons with a dual psychiatric disability or autism spectrum disorder. The Gippsland Carers are calling for a fighting fund to take the government on at the polls.

Understanding Autism

Warrnambool Standard, Australia - 21 May 2006

... At the conclusion of **Autism** Awareness Week (May 14 to 20) Miss Chilton revealed the difficult learning curve of watching her two autistic sons grow. ...

www.the.standard.net.au/articles/2006/05/22/1148150154361.html

WHEN single mother Julie Chilton deals with her child's errant behaviour in the street she is all too aware of the judgemental glances of many passers-by.

But the Warrnambool mother of two autistic boys said that when one of her children "flipped out" it wasn't a case of bad mothering.

"I wish people could just understand it's not that easy," she said.

"It is something only I can know. It's very difficult for other people to understand until they live with it."

At the conclusion of Autism Awareness Week (May 14 to 20) Miss Chilton revealed the difficult learning curve of watching her two autistic sons grow.

⁷ http://www.aph.gov.au/senate/committee/mentalhealth_ctte/report02/report.pdf (151Kb)

⁸ http://www.aph.gov.au/senate/committee/clac_ctte/cstda/index.htm

Jake McConnell, 7, and his brother Nathan, 5, were both diagnosed with autism, a disorder which affects communication and social interaction skills.

Miss Chilton said Jake's unusual social behaviour and fear of loud noises were the first signs of his condition.

For Nathan, the development of a brain tumour at 12 months led to the disorder, which has left him unable to walk, talk or eat by himself.

"I just take it as it comes every day and I've got to the point that I'm used to it. You learn to deal with it and get into a routine, into a pattern," she said.

"I never stop learning with it, there is something different that happens every day."

She said because of her children's illness she would never be able to return to work because Nathan needed 24-hour care.

Despite the illness it was rewarding to know she had two very happy little boys who loved life. "They get on so well. They are the best of friends."

"It would just be nice if others would take time out to understand them. I feel very lucky because they are happy kids."

A family barbecue was held at MPower yesterday to celebrate Autism Week.

Chief executive Kerry Nelson said autism was a lifelong disorder but those with it were capable of a great deal.

She said increased community support and understanding of their individual needs would help them achieve their full potential.

www.theage.com.au/news/national/terrible-toddlers-facing-kindergarten-bans/2006/05/20/1147545567978.html

Toddler Expulsion

By Deborah Gough
May 21, 2006

MORE than 100 Melbourne toddlers are threatened with expulsion or exclusion from kindergarten or child care each year because of aggressive, disruptive or anti-

social behaviour — yet the state's only program that works long-term to deal with such behavioural problems is facing closure.

Kindergartens and child-care centres fear aggressive or violent behaviour is increasing in children aged from two to six. They say it is prevalent across Victoria and rising among children from wealthier families.

In one incident in the southern suburbs, a three-year-old boy acted out scenes from pornography he had seen at home.

Teachers and child-care workers increasingly deal with children as young as two displaying such aggressive behaviour as hitting other children, biting, punching, pinching, destroying toys and equipment, and threatening teachers, workers and other children.

Despite the growing problem, the Connections Working Together program, a children's and family service run by Uniting Care, faces closure in six weeks because of a lack of funding.

The program helps about 150 children a year in the southern and eastern suburbs.

About 40 per cent of those children are at risk of being expelled or asked to leave kindergarten or child care. The rest are often shy or withdrawn and refuse to participate in activities.

The program's closure would force many parents to remove children from pre-school care or education rather than risk further disrupting classes or traumatising the child.

Connections' director of Eastern Early Childhood and Community Services, Caroline Lovell, said the program was in jeopardy because the Federal Government had refused to say if there would be funding next financial year.

Connections would talk to parents, kindergartens and child-care centres next week and would need to give program staff notice of termination, Ms Lovell said.

The service had tried to resolve a three-year, \$1.5 million funding gap with the Department of Family and Community

Services and with the office of the Minister, Mal Brough, Ms Lovell said.

Kindergarten Parents Victoria chief executive Gerard Mansour said children needing help with behaviour problems were not limited to the southern and eastern suburbs.

While no statistics were kept on the issue, he estimated that more than 100 children were at risk of being excluded from kindergartens and child-care centres across Melbourne.

He had not heard of children being expelled but said teachers and workers either suggested parents remove their children or "soldiered on".

Mr Mansour said the increase in problems was caused by pressures on busy families, family breakdown and lack of community support in parenting and at kindergartens and child-care centres.

The program was needed because the Victorian Department of Human Services' Kindergarten Inclusion Support Service was only to treat children diagnosed with autism, attention deficit disorder and disabilities.

He called on the State Government to widen the definition of children in need of help and increase funding for its program by 25 per cent.

Craig Clarke, a spokesman for the federal minister, said the program was under review; he would not be drawn on its imminent closure.

Teacher and director at North Ringwood Community Children's Centre Alison Gorman said the service was essential.

"We would be devastated if that service wasn't there any more," Ms Gorman said.

"We are talking about behaviours that are more pronounced than normal, that need specialist strategies both at home and at kinder."

The program has been assessed by Dr Tim Moore, senior research fellow for the Centre for Community Child Health at the Royal Children's Hospital.

His report showed that if emerging difficulties were left untreated, more severe problems were likely to develop later.

Dr Moore said the program improved behaviour, increased parenting and staff skills and allowed children to either stay in or return to kindergarten or child care.

A Department of Human Services spokeswoman said it had allocated \$3.7 million to a pre-school field officers program. But Ms Lovell said that program was only for kindergartens and was more of a co-ordinating role, offering only 11 hours of support.

The Australian Education Union's vice-president of early childhood, Rosalie Kinson, said kindergarten teachers dealt with serious behaviour problems and she knew of one case where a child carried a knife in his sock.

"I know that the public image of little children is of little angels playing happily but there are children that present at pre-school who have significant behaviour issues and often it is the kindergarten teacher who is the first to see that there is a serious problem," Ms Kinson said.

Access and Airlines

Disability access standards and airlines

Tuesday, 30 May 2006

Statement by Human Rights and Acting Disability Discrimination Commissioner Mr Graeme Innes AM

The Human Rights and Equal Opportunity Commission has received several media requests for comment on Virgin Blue's proposed Carer policy. The Commission is not able to make detailed comments about the policy because it may be subject to complaints to the Commission.

However, the following background information is supplied on federal standards for disability access to public transport as they relate to airlines.

Re: Boarding

The Disability Standards for Accessible Public Transport recognise (clause 3.3) that because of design restrictions in aircraft, people may not be able to enter using their

own wheelchairs and similar mobility aids. (Note: the Standards, made under the Disability Discrimination Act, came into force in 2002)

The standards, however, require that the operator of the conveyance must ensure equivalent access by direct assistance to passengers (except for small aircraft where even this may not be possible or safe) - but only if it can reasonably be provided without causing the transport operator "unjustifiable hardship".

If an airline requires a passenger who can freely move with his or her wheelchair to transfer from that chair to an airline one that does not give independent mobility, the airline would have to provide direct assistance unless it would cause the airline unjustifiable hardship.

Although the Commission has previously accepted arguments from small carriers or those with no cabin crew that assistance on board aircraft would impose unjustifiable hardship, there has been no such decision under the Disability Discrimination Act involving larger airlines or assistance within terminals.

An airline might argue that they should be exempt from the standards on safety grounds but such a claim would need to be carefully considered including thorough consultation with the public and with other relevant regulatory bodies.

Re: Access to toilets

Virgin Airlines has also referred to concerns regarding assistance in providing access to toilets. Accessible toilets are required to be provided only on wide body twin aisle aircraft in further recognition of design constraints (clause 15.5). For these aircraft it is specified that direct assistance to the toilet door must be provided - since a passenger using a wheelchair will be using an aisle chair rather than their own chair.

Media enquiries: Janine MacDonald (02) 9284 9677 or 0407 660 235

For information about the Commission's complaint process, go to:
http://www.humanrights.gov.au/complaints_information/index.html

SBS wants your experiences

SBS wants to hear about your experiences with Autism Spectrum Disorder

My name is Antoinette Currah and I am a producer with SBS TV's News and Current Affairs forum INSIGHT.

INSIGHT is a unique Australian television program - a discussion forum focusing on a single issue with the participation of a studio audience.

I am in the research stages of preparing this forum which will be filmed on Tuesday 25th July at our Sydney studios. The forum will canvass a range of views from increases in diagnosis, best treatments, funding issues, mainstream education to name a few.

I am looking for families to speak to me about their situation and their concerns for possible inclusion in the studio forum. On top of that, I am looking to produce two or three tape stories.

Feel free to forward this email to families you think would be interested.

I look forward to hearing your stories and I am happy to answer any other enquiries.

Many thanks, Antoinette Currah

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A Parent's Advice

If among the many pieces of advice – and words or warning - you will receive as the parent of a child with Asperger Syndrome you only take on a handful, let these two be among them;

Entry into high school is fraught with extreme danger.

Begin a diary the during the transition period before your child leaves primary school and during the first year of high school.

This is not meant to scare you. This not meant to threaten you. This is a fact, and unless you are prepared for it all hell could come down on you. Be prepared.

For some reason my wife began such a diary when our son headed towards high school.

The following is – for obvious reasons I would think – only the letter traffic from us to the Education Department, and not the department's replies.

However please rest assured that nothing in this first letter has ever been disputed by the Education Department. The principal at the high school concerned was transferred the following year to a desk job within the department.

The autism association in described the school in an open meeting as the worst it had come across.

The letter was written after the “event”, not during the heat of battle. That is worth keeping in mind should anything approaching this situation come your way.

December 18, 2000

The District
Superintendent,
Education Department.

Dear Sir,

We are writing to express our disappointment at the way in which the school handled the management of our son during the 2000 school year.

Our son was diagnosed . . . with Asperger's Syndrome in October 1999.

We took immediate steps to make the school aware of the situation, given that he was starting Year 7 in 2000. At the transition meeting with staff from the school and the Primary School, we were assured because of our son's needs the necessary Negotiated Curriculum Plan would be in place from day one.

We were also advised that our son would be put into a class which would focus on children with special needs, but not a “special” class as such. We were told the teacher was a special education teacher, and that a support teacher would also be on hand to help.

Shortly after the start of Term 4 we felt we had no choice but to withdraw our son from the school, for the following reasons:

The school's failure to implement many if not all of the suggested strategies provided by us, based on a sound knowledge of the management of an Asperger child.

The school's failure to maintain any of the implemented strategies for anything more than a few weeks, contrary to all published material on Asperger Syndrome - provided to the school – that Asperger children require continuity, not “set and forget” strategies.

The school's failure to protect our son from systematic bullying and harassment or to acknowledge that he was the target of systematic bullying and harassment.

The school's failure - to the extent of reluctance - to make itself aware of Asperger Syndrome and of strategies to help our son. This ranged from declining to purchase the acknowledged authoritative texts, to declining to attend or make someone available to attend a two-day weekend authorised workshop in June on handling Asperger Syndrome at nearby (It was mentioned to us that one of the teachers had tennis on Saturdays.) The school also seemed reluctant to invite a representative from the Autism Association to address the teachers, despite such a person being available, and despite offers by the association and repeated requests from us. The school also declined to contact our son's previous school or his tutor, a qualified special education teacher himself - both of whom were willing to offer strategies and/or work with his teacher in helping our son.

Much of this neglect resulted in our son developing serious behavioural problems, which seemed to surprise no one with any knowledge of Asperger Syndrome. Except of course the school, and the school handled the situation poorly. The school's response was, not surprisingly, to suspend our son on a number of occasions. The school's solution was - with consultation - to set in place strategies, many of which were simply left to fall away within weeks.

The cycle of harassment and bullying, with our son responding with more violence or threats of violence against a group of boys - one in particular - would then begin again, and we were back to square one. The school's agenda at all times - to us at least - seemed to be to introduce strategies that would bring our son into line, into the mainstream.

Anyone with any knowledge of Asperger Syndrome knows this was never going to work.

Despite us collecting, collating and providing detailed published material on Asperger Syndrome to the school for the teachers, we firmly believe little or any of it was ever read. In fact we are fairly certain that many of his teachers didn't even bother to read his NCP.

A strategy was put in place whereby if our son's teacher could see he was going seriously off-track, we could come and get him and take him home before trouble developed. The school seemed to enjoy using this strategy, but it seemed more of a way for the school to remove the problem rather than attempt to deal with it.

In late July, out of frustration, we contacted the Education Department ourselves to inquire if the school was accessing everything it could to help our son. We were eventually put on to XXXXX at the Department of Education, Training and Employment. We detailed the above concerns to her, and she seemed amazed that the school had failed to act on the strategies we had provided. Her support and professionalism, while maintaining the interests of our son foremost, has possibly been life saving. DETE acted in late Term 3 to ensure the correct strategies - many of which we had initially suggested in Term 1 - were put in place for the remainder of Term 3 and for Term 4, and worked with the Autism Association to ensure the strategies were maintained and were working. The intervention was everything we had been hoping for, but unfortunately it was too late. Our son's mental state was close to breaking point because of what even he saw as the school's failure to act to prevent the constant harassment and bullying. After another incident early in Term 4 involving our son reacting violently to more bullying and harassment, followed by a suspension, we were invited to the school to discuss his re-entry.

Before attending the meeting we decided the situation was never going to improve, and we informed the school at that scheduled meeting on October 31 that he would not be returning. There was no attempt by the school to talk us out of our decision. XXXXX from DETE then set in place a means to transfer our son to (another) High School, in transition this year and hopefully full-time next year.

A number of incidents have added insult to injury. We were asked by the school to provide a supporting letter from our son's paediatrician as to why he should be withdrawn from the school. The school's reply to Dr Lamb from the deputy principal was quite simply misleading to say the least. To wit: ... support programs ... have been developed and put into place to cater for (the student's) disability ..." "Development of these plans and strategies has involved

working closely with the Director of Disability Services and representatives with expertise in Asperger Syndrome ... " ...and ... "These plans have been developed after much consultation ..." Such statements imply a pro-active stance by the school in relation to our son. This, as far as we are concerned, is far from the truth. Yes, all that was in put place, but only after we approached the Education Department in late July, and XXXXX and the DETE intervened in late August to force the school to act. The letter was both an insult to our intelligence and a flagrant distortion of the school's handling strategy for our son. Then, shortly after we withdrew our son from the school we received a letter from the school asking us to consult with them regarding a new NCP for him. Attached to the letter was an NCP for the child who had been the main instigator in bullying our son from as far back as a transition visit in

1999. We returned the NCP to the school and pointed out how inappropriate it was for another child's NCP to be sent to us. A member of the administration staff indicated to us that it was hoped we would not reveal the contents of the NCP, or even that it had been sent to us in error. Thirdly, no one from the school who was involved with our son has approached us since to inquire as to his health, his progress, or in any other way. This is despite regularly being at the school on other matters, including working in the school canteen where contact with school staff is common. We have been ignored. We feel let down, we feel humiliated, and yes, we are angry. Our son feels let down and humiliated, but at least he is getting over his anger. It has now been eight weeks since we withdrew him from the school. After visits to his paediatrician and a psychologist, and the love and support of his family, he is finally getting to the stage where he can laugh again, and not threaten to end his or even our lives at the slightest hint of criticism. Our son had a right to feel safe at school. Through the school's inability to cope with his Asperger Syndrome, and more importantly the school's lack of willingness to accept or even seek assistance until it was forced to accept help, the school quite clearly failed to create a safe environment for him. We will not know for some time how much his year at (school) has injured him.

His visits to (his new school) have been very positive and we feel and hope that this move will be in his best interests.

We bring these matters to you as concerned and frustrated parents, and to place our concerns and frustrations on the record.

We would be available should you want further details or information.

Yours sincerely,
PARENTS

Accusations of Munchausen

Autistic Spectrum Disorders and the Risk of Accusations of Munchausen Syndrome by Proxy

Helen Hayward-Brown PhD.

Many parents are unaware that they are at risk of being falsely accused of Munchausen Syndrome by Proxy (MSBP) in relation to a child's autistic spectrum disorder. Munchausen Syndrome by Proxy is purported to be a behaviour where the mother makes her child ill or fabricates a child's symptoms, in order to get attention from the medical profession. Other labels are: fabricated and induced illness, factitious disorder by proxy and paediatric falsification disorder.

Despite the recent decision of the Queensland Supreme Court (*R v LM* [2004] QCA 192) that MSBP or Factitious Disorder by Proxy is not a recognised disorder, making psychiatric and paediatric evidence in this regard inadmissible, many professionals are using an 'invisible label'. The mother is profiled as MSBP, but the label is not attached. This means that many parents are accused or suspected of MSBP without knowing.

Some of the components of profiling include: the mother is knowledgeable about medical terminology and shows interest in medicine, the mother is working or has worked or studied in a medically related area, the mother is 'over-protective', the mother asks too many questions of health professionals, the mother is not compliant (ie. She is assertive), the mother has visited too many doctors ('doctor shopping') and/or has presented too many times to hospital with her child, the mother has used alternative health practitioners, the mother has a 'personality disorder' or engages in 'emotional abuse' of the child. A parent who has debated the medical diagnosis of her child or who has made any complaints about treatment is particularly at risk of an accusation.

My recent research and fieldwork in relation to these matters identifies parents of autistic spectrum disorders as one of the groups of high risk in relation to accusations. In particular, parents will be targeted if they agitate for more support for their child from educational or health authorities. When parents are accused of MSBP, their child or children may be removed from their care and placed with a foster family. In the children's courts, harm to a child does not have to be proved. Courts operate on a 'balance of probabilities' and if there is any notion of 'risk' of harm, then the child may be removed from the parents.

For further information contact Dr Helen Hayward-Brown: email address heleneli@pnc.com.au or visit www.pnc.com.au/~heleneli.

Other useful links:

www.msbp.com

www.falseallegation.org

www.fightcps.com

www.mindd.org

Dr Helen Hayward-Brown is a medical sociologist/anthropologist who completed her doctorate on false accusations of MSBP. She has completed two short-term post-doctoral fellowships at the Social Justice and Social Change Research Centre at the University of Western Sydney. She is also a trained teacher and counsellor. Dr Hayward-Brown is currently teaching sociology of health and ethical issues at UWS, completing some further research work, and consulting with lawyers and families in relation to false accusations of MSBP.

Important Inquiry

The government is holding another Inquiry (see below). Here are some relevant links:

- The agreement between the federal and state/territory governments about funding and providing disability services is the Commonwealth State/Territory Disability Agreement (CSTDA) 2002-2007 - [PDF \[145kb\]](#) | [RTF \[583kb\]](#)
- Disability services are supposed to meet the National Standards for Disability Services (1993) - [PDF \(85kb\)](#) | [RTF \(45kb\)](#) or <http://www.facs.gov.au/internet/facsinternet.nsf/disabilities/policy-nsds1993.htm>. Surely these standards are meant to be a joke ... but it just is not funny. There is no monitoring of the standards ... the states self-assess whether they meet the standards ... and of course they say they do. You might like to read the standards, see what you think of them ... and see whether the disability services you get meet the standards.
- There is a lot more information, including stuff about your state at <http://www.facs.gov.au/internet/facsinternet.nsf/disabilities/policy-cstda.htm>

So if you have any comments at all about the government funded services you receive (or not), how about writing to the committee (see below). They are keen to hear from you.

And tell me (email to convenor@a4.org.au) what you would like me to say in a submission from A4.

SENATE COMMUNITY AFFAIRS REFERENCES COMMITTEE

INQUIRY INTO THE FUNDING AND OPERATION OF THE COMMONWEALTH STATE/TERRITORY DISABILITY AGREEMENT

Terms of Reference

On 11 May 2006 the Senate agreed that the following matter be referred to the Community Affairs References Committee for inquiry and report by 7 December 2006.

An examination of the funding and operation of the Commonwealth-State/Territory Disability Agreement (CSTDA), including:

- (a) an examination of the intent and effect of the three CSTDAs to date;
- (b) the appropriateness or otherwise of current Commonwealth/State/Territory joint funding arrangements, including an analysis of levels of unmet needs and, in particular, the unmet need for accommodation services and support;
- (c) an examination of the ageing/disability interface with respect to health, aged care and other services, including the problems of jurisdictional overlap and inefficiency; and
- (d) an examination of alternative funding, jurisdiction and administrative arrangements, including relevant examples from overseas.

Written submissions are invited and should be addressed to:

*The Secretary
Senate Community Affairs References Committee
PO Box 6100
Parliament House
Canberra ACT 2600*

Closing date for the receipt of submissions is **4 August 2006**.

The Committee prefers to receive submissions electronically as an attached document - email: community.affairs.sen@aph.gov.au or phone (02) 6277 3515 for more information.



AUSTRALIAN SENATE

COMMUNITY AFFAIRS

REFERENCES COMMITTEE

PO Box 6100 PARLIAMENT HOUSE CANBERRA ACT 2600

Tel: (02) 6277 3515 Fax: (02) 6277 5829

Email: community.affairs.sen@aph.gov.au

Website: www.aph.gov.au/senate_ca

17 May 2006

The Senate has referred to the Committee a range of matters relating to the funding and operation of the Commonwealth State/Territory Disability Agreement for inquiry and report by 7 December 2006. The terms of reference for the inquiry are attached and are also available on the Internet at http://www.aph.gov.au/senate_ca

The Committee invites you to provide a written submission addressing any or all of the issues that may be of relevance to you. The submission should be lodged with the Committee Secretary, at the above address by 4 August 2006. The Committee prefers to receive submissions electronically as an attached document – email: community.affairs.sen@aph.gov.au – or by hard copy to the above address.

Submissions become Committee documents and are made public only after a decision by the Committee. Publication of submissions includes loading them onto the internet and their being available to other interested parties including the media. Persons making submissions must not release them without the approval of the Committee. Submissions are covered by parliamentary privilege but the unauthorised release of them is not protected.

Following consideration of submissions, the Committee will hold public hearings. The Committee will consider all submissions and may invite individuals and organisations to give evidence at the public hearings.

Information relating to Senate Committee inquiries, including notes to assist in the preparation of submissions for a Committee, can be located on the Internet at http://www.aph.gov.au/senate/committee/wit_sub/index.htm

Should you require further information please contact me on (02) 6277 3515.

Yours sincerely

A handwritten signature in black ink that reads "Elton Humphery".

Elton Humphery
Committee Secretary

Autism and the Federal Budget 2006/7

The 2006-07 Budget does not mention autism or ASD.

Christopher Pyne MP's website says he is responsible for Autism. When I pointed out the omission of autism/ASD from the Budget, a staffer in his office referred me to a Budget initiative from FaCSIA entitled **Better care for people with mental illness and people with disabilities**⁹.

The detail indicates this initiative is limited to or specifically targets people with mental illness or an intellectual disability.

The ABS 2003 Survey of Disability, Ageing and Carers showed there are over 30,000 people with autism. The AIHW reports on CSTDA MDS data that shows people with autism have difficulty accessing suitable respite. But this initiative will help with respite for just 15,000 people with disabilities (not just autism). The initiative leaves significant levels of unmet need among the most disabled citizens.

An AIHW publication shows people with autism report the highest level of disability. The initiative says: "Priority access will be given to elderly parents who live with and care for children, including adult children, who have a severe mental illness or an intellectual disability."

Most people with an autism spectrum disorder do not (yet) have elderly parents and many do not have intellectual disability, so despite their substantial need they are excluded from this initiative.

This shows the government did not listening to people with ASD or their advocates. Most carers would prefer to get their respite while their child attends effective early intervention or is appropriately supported in their community. Respite is not a top preference in what ASD advocacy groups ask for.

According to the FaCSIA website, Mr Brough said in part the initiative is "to provide flexible funding for projects which assist families, children and young people affected by mental illness." Since governments do not regard autism spectrum disorders as mental illness, people with ASD will not be supported. In practice, the mental health sector typically excludes people with ASD from mental health services even if the person with ASD also has mental illness that requires treatment.

The website says the initiative is supposed to focus on "prevention and early intervention". But none of the elements of the initiative (that is, "improving accommodation arrangements", "more respite care places", "personal helpers and mentors to assist people with mental illness" and "community based programmes to help families coping with mental illness") is a recognised approach for "prevention and early intervention" in relation to autism spectrum disorders.

For people with autism, "prevention and early intervention" depends on intensive intervention immediately following diagnosis. Diagnosis of autism mostly occurs under 6 years of age but the detail says the "focus will be on projects that support young people [with mental illness] aged 15-24". This leaves a major gap in services for people with autism under the age of 15 years.

People with autism and their families can be deeply disappointed by government. They can reasonably conclude that the government's response to autism/ASD in the 2006-7 Budget shows our government wants little to do with the most disabled members of the community.

Bob Buckley

⁹ http://www.facsia.gov.au/internet/minister3.nsf/content/budget06_better_care_for_people_with_disabilities.htm

Letters / Emails

Please send letters to edit@a4.org.au. Letters sent to the editor may be published unless they are clearly marked "not for publication". Normally, they will appear with your full name and state unless you mark them clearly "anonymous" or "first name only".

Well, this was today.

Finally...D day...D being for DX. We'd done the social worker/psychologist lead up thing...all good. Jake has been ill (with the flu and some asthma) but after a three year wait there was no way he was missing out on going down to Perth unless he was squirting arterial blood.

So we went.

Stayed down at my mothers in Perth the night before (always a good idea so that we don't have to leave at five am). Agisted other kids out all over the wheatbelt. Then quite happily went in for the assessment.

You gotta remember that I have an older boy who is seventeen and Jake all over again. Or rather Jake is him all over again. Never having received a diagnosis, I thought, was something that made not the least little bit of difference. It was pretty well the school bus and classroom situation that prompted us to seek a diagnosis.

So we did the assessment. Two way glass, teams of specialists, students as observers...and Jake. Who did pretty well, considering - although how do you assess 'doing well'? He was noticeably anxious and upset when the psych questioned him about having friends, and that was painful to watch. There were other questions about emotions that he didn't know quite how to answer, and that upset him too - he thought he was flunking out.

There was a rather special little moment when he realised that the two way glass was actually an observation aid (bless American cop shows!) and started grilling the medicos about microphones, the glass, and 'spying on him'...then quite a few hours later it was all over.

Now this is the weird bit. They had prepared me for the whole diagnosis thing - 'what will your reaction be if you receive an 'unfavourable' diagnosis?' the social worker asked; my response...'Drown him in a bucket like a kitten. Well, what did you EXPECT me to say?'

But when they called me in for the result, it felt a little bit like I was on the receiving end of a diagnosis involving a terminal illness; 'You have a majestic tumour growing in your right ovary, and have three minutes to live.' There were grave faces, six of them (the rest had respectfully bowed out backwards in deference to the solemn occasion). I wondered if they'd sealed the windows so I couldn't jump out of them.

If you remember, the provisional diagnosis was Asperger's. The one they came up with was PDD-NOS. Didn't see that coming, but Jake has improved so much with social skills training and just getting older that I was pretty happy with that. Well, I was til I looked back at their faces. Then the social worker started 'counseling' me, and I felt AWFUL.

The overlying message was that 'There is something wrong with your child.' I guess I have always known there is something different about both kids, but have never seen it as being WRONG. Jake had all sorts of questions too at the end of the day (uncharacteristically) - he picked it up too.

All in all, by the end of the day I was nearly in tears. I picked up the seventeen year old and said, 'Should I have got you diagnosed, d'ya reckon?' He said, 'Will I get more money from Centrelink?' Typical kid. Even for a non-typical kid.

I feel really, really bad about Jake going through the day. It was hard for him. He knows that other people have friends, and he wants them too.

One of the weird, but in some ways fathomable, things he said today was, 'Nobody ever blames God. Cos everybody likes him.' I hope that going through all this will have helped. And I hope that people won't look at him differently now he has a 'tag'.

All this for a piece of paper. Hope it was worth it.

Cheers Samantha

A Parents Story

My child is now 13 yrs of age and was diagnosed with AS when 7.5yrs of age.

My boy is what I called "my bull in the China shop child". He barrels through everything, shops, home, etc, he doesn't think he is doing this and when we ask him to slow down or to wait for the space to get bigger before pushing your way through, he says "I got through didn't I"

He rarely slept more than 30-45 minutes twice a day; he was and still is a very restless sleeper. My first full night sleep was when he was 6.5 yrs of age.

He talks constantly repetively on what is his latest "obsession". At the moment it is his style of music he is into. Heavy metal mostly.

He will hear an interview or read an article on someone and tell you that this is the truth about this person. Even if you know of this person or have read or seen more than he has, he finds it very hard to acknowledge your input into this. He truly believes that he is right and no-one else knows better than him.

I can hear people say" ahh but that could be an age thing" and yes, it could be, but when it continues on and on for weeks, then it doesn't seem like an age thing, more like repetitive annoying, you want to gag him thing.

He does have trouble "expressing" himself and will often use words in the wrong context, and again is not happy to be corrected.

He started Secondary school this year, and we had the first term very unsettling. He was suspended twice in the first 2 weeks. He didn't understand why, as he felt he had said or done the right thing.

He very often talks out aloud, and I mean loud, we quite often have to tell him to put his voice down as he is too loud. He doesn't think he is, his hearing is fine, so we know that isn't a problem. He talks in his sleep, when he finally falls asleep, he is quite often awake till around 11pm of a night most nights. He will now listen to music in his room whereas 6 months ago he would be in and out of bed like a yoyo.

So I guess having him listening to music is better than being a yoyo half the night.

We are constantly telling him, even at 13yrs of age, how to behave when we go somewhere, how to share and not to gobble down his food like it is his last meal; how to sit at a table, not with a leg up on the chair and slouching. Again people might say this is an age thing, once or twice I would say yes, but consistently it gets very upsetting to keep repeating yourself and you don't enjoy your own meal because of constantly trying to get this child to at least sit up straight to eat.

He will eat his food with his fingers given the opportunity, he doesn't like to use a knife and fork, I'm not sure why. We do expect him to use utensils and he will but grudgingly. Maybe we should ignore this, but I feel he needs to know what is acceptable.

We are constantly teaching/talking/arguing with our boy on just the basics of life, on how to be able to go out and be accepted and what is not acceptable.

Mind you, there is so much we have learnt as parents; I know I am a more accepting person to others, more able to think that maybe this person/child has an "issue". I'm more open-minded to what I used to be.

I love my boy, he is the world to me and some days I would love to have a child less challenging, but most days, I'm grateful for who he is and that even though he is on medication, the cheeky loving child he is, is still there.

Kayleen

A4 Contacts

A4 is a grassroots organisation. All A4 activity, such as publishing the Updates (newsletters), is done by volunteers. Please understand that A4 volunteers may have no training or qualifications for their various roles. They do the best they can for people with ASD, their families and associates. A4 welcomes assistance and constructive criticism.

Update team: edit@a4.org.au

Editing team: Juanita and Vicki

Reporting team: we currently have vacancies in all states

Production team: Helen Curtin – proof-reading (Qld), Bob Buckley – distribution (ACT).

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