A4 UPDATE
Autism Aspergers Advocacy Australia

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Issue 2

Autism, behaviour and discrimination law

No one can say what Australian discrimination law means for people with autism. The High Court's *Purvis v New South Wales (Department of Education and Training)* ([2003] HCA 62) decision has left a state of confusion. It denies people with the most disabling autism any prospect of a successful discrimination complaint.

With good reason, there is widespread belief that Australian law provides little or no protection for people with autism. Following is my understanding how things currently stand …

The Productivity Commission summarises the developments (page 302).

> Box 11.1 **Behaviour as a disability in the Purvis case**
>
> Daniel Hoggan, the foster child of Mr and Mrs Purvis, was enrolled in a mainstream Year 7 class at Grafton High School in 1997. Daniel had multiple, complex disabilities due to a severe brain injury in infancy. During 1997, he was disciplined and suspended on several occasions for verbal and physical abuse of teachers, teachers' aides and other students. The school recommended Daniel be moved to a special education unit.
>
> The New South Wales Department of Education rejected an appeal from Mr and Mrs Purvis against this move. The Purvis' made a disability discrimination complaint to HREOC, which found in their favour, and the case then proceeded through the courts.
>
> - HREOC found the Department of Education had discriminated against Daniel on the ground of his behaviour and therefore on the ground of his disability.
> - The Federal Court disagreed with HREOC. It said 'the behaviour of the complainant is not *ipso facto* a manifestation of a disability within the meaning of the Act'.

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Disclaimer

- The Full Court of the Federal Court agreed with the first Federal Court decision. It said Daniel's 'conduct was a consequence of the disability rather than any part of the disability within the meaning of section 4 of the Act'. That is, Daniel's behaviour was separate to his disability, even though it was caused by the disability.
- The High Court said Daniel's conduct was part of his disability for the purposes of the DDA because it was 'disturbed behaviour' under part (g) of the definition. It said the Federal Court had erred in distinguishing between a condition and its behavioural manifestations. However, for other reasons, the majority of the High Court found that the Department of Education had not discriminated against Daniel.

See http://www.pc.gov.au/inquiry/dda/finalreport/index.html

In relation to the "other reasons" for the High Court's majority decision, the Productivity Commission said (page 303) …

> *The DDA includes a number of defences that allow disability discrimination in certain circumstances. Direct discrimination, for example, may be lawful if providing different accommodations and services would cause an unjustifiable hardship (see chapter 8). Indirect discrimination is lawful if the rules or conditions that have a disproportionate effect on the person with a disability are otherwise reasonable in the circumstances (section 11.2).*

The "certain circumstances" can relate to the comparator. The Purvis case ruled that the comparator is a person who does not have the disability but who behaves the same way. So the legal test for discrimination relating to autism is whether the treatment in question is reasonable treatment of a person who does not have autism but who behaves the same as someone with autism. The Productivity Commission said (page 309)…

> *The High Court's majority finding of no direct discrimination rested largely on its view that the comparator was a (hypothetical) student exhibiting 'wilful' behaviour similar in outward appearance to Daniel's 'disturbed' behaviour. …*

Someone who behaves the same as someone with autism could be diagnosed with autism. It is unlikely someone who does not have autism could behave wilfully the same as someone with autism … and if they did, many people would regard almost any adverse treatment as reasonable, given the type of advice members of the public often give to parents of children with autism.

> The majority view of the High Court regarding the comparator in the Purvis case appears to imply that different treatment of a person with a disability on the ground of the behaviour caused by their disability cannot constitute direct discrimination … (page 309)

This says under the current DDA there could never be a finding of direct discrimination in relation to a person with autism (page 310).

> *The Productivity Commission considers that these concerns would be addressed in part by its recommendation to introduce a general obligation to make reasonable adjustments for people with disabilities, excluding adjustments that would cause unjustifiable hardship. This would apply to both pre and post enrolment situations in education, and to all other areas of activity covered by the DDA (see chapter 8).*

While this "in part" recommendation may help some people with a disability, it does little to help people with autism. Besides, the Government's response was dismissive.

> The Government considers that the current definition of disability includes such behaviour. The High Court's decision in *Purvis v State of NSW (Department of Education and Training)* 2003 HCA 62 clarified this.
>
> However, the Government accepts the Productivity Commission's observation that it may be valuable to remove any remaining confusion and accepts its recommendation that an advisory note be added to the definition to clarify the issue in line with the High Court's decision.

See the AG's website (html, PDF or MS Word)

To my knowledge, the Government has yet to add such an "advisory note" to the DDA. It is remarkable that a Government claiming the high ground on the economy chose to dismiss and ignore advice from the Productivity Commission on this matter.

The Productivity Commission found (11.4, page 315)

> *The proportionality test in the definition of indirect discrimination in the* Disability Discrimination Act 1992 *(s.6(a)) is unnecessarily complex and places an unwarranted burden of proof on complainants.*

Even when the proportionality test is removed, as in the *ACT Discrimination Act*, the legal system has failed repeatedly (annotated decisions for seven matters in the ACT Discrimination Tribunal can be downloaded from here).

The suggested changes to definitions or comparators would not help people with autism. The quotation above (from page 303) says "Indirect discrimination is lawful if the rules or conditions that have a disproportionate effect … are otherwise reasonable … ". Since autism is reported as having the highest reported rate of severe and profound disability, it is more likely that people with autism will need accommodations that "have a disproportionate effect". So discrimination against people with autism is often lawful.

The meaning of the legislation is unclear. In April 2004, the Senate Legal and Constitutional Legislation Committee, in its report on *Provisions of the Disability Discrimination Amendment Bill 2003* said (page 17)

> 2.41 When asked about evidence regarding the *Purvis* decision, the representative [from the Attorney-General's Department] stated:
>
> > To say that it is now lawful to discriminate on the basis of behaviour, which is the condensed version of what some of the evidence was, I would submit, is an oversimplification. It is not quite that simple.
> >
> > What is required is a consideration of the circumstances of the person with the disability, the circumstances of the alleged discriminator and a whole range of issues come in there and the circumstances of a notional person without the disability who exhibits that behaviour. That is why I say bear in mind that the court there was dealing with a clear case of very extreme behaviour.
>
> …
>
> 2.43 The Committee notes that no clear answer to the question of a behavioural threshold was provided by the Department.

Another commentator says

> … *Purvis* was not run as an indirect discrimination case. Moreover, it would have been difficult to establish that the requirement that Daniel behave appropriately was an unreasonable requirement.

Kate Rattigan, *A Case for Amending the Disability Discrimination Act 1992 (Cth)*,
Melbourne University Law Review, see
http://beta.austlii.edu.au/au/journals/MULR/2004/17.html

[Note: "difficult" is legal jargon for "impossible for mortals"]

This means "indirect discrimination" against people with autism, especially people with high needs due to their autism, is usually lawful.

There is no other process to protect their right to access essential services for people who are severely disabled by their autism. There is no legal protection of the right to treatment, rehabilitation, education, etc. for children with autism in Australia. There is no *safety net* for essential services; no *provider of last resort* … whatever.

Some existing service might be seen mistakenly to function as a safety net. For example, some people may think that special schools provide a safety net in the area of education. Yes! For some children with higher needs, they offer a service that suits some children with special needs better than existing mainstream schools.

Special schools largely exist because state governments need to be able to show there is an educational placement for every child. In most cases, Governments regard special schools as too expensive and close them as quickly as possible.

Section 45 of the DDA protects Special Schools and other “special measures” from discrimination complaints. There is no reasonableness or any unjustifiable hardship tests in this area. “Special measures”, where they exist, discriminate just as they choose.

This is not to say that special schools and special measures are all bad. There are many deeply dedicated and generous people working in these settings. Most of them do their very best with the resources they are given for their students/clients. Many parents appreciate enormously the education provided in some special schools.

But it is rare for a special school to offer best practice: there are no national benchmarks for special needs students, there is no outcome or standard compliance monitoring and reporting. Political pressure for increased productivity, for privatisation of services and the profit/efficiency motive can easily obliterate any such services. The special schools that remain are all at imminent risk of closure.

Governments (both state and federal) are transferring safety net responsibility to families. For example, education administrators suggest increasingly that families home-school their autistic child (at the family’s expense … while paying taxes that provide services for everyone else’s children). The federal Health Department advises that children with autism need 20 hours per week of (largely clinical) intensive early intervention for a minimum of two years, but no government funded agency offers a service in Australia even remotely approaches this: governments leave it to parents to meet this need … in addition to their 24/7 intensive supervision role.

Nor is the Purvis decision just about education; it is far reaching. For example discussion of workplace relations says:

> Although *Purvis* was a disability discrimination case, the same argument should apply to any protected attribute. For example, a requirement that all employees must be available to work full time should not be taken as directly discriminatory of those having family responsibilities. The fact that the need to work part-time often flows as a matter of necessity from family responsibilities is not sufficient. The proper approach is to apply the indirect discrimination test and ask whether the full-time requirement, impacting as it does on those with family responsibilities, is unreasonable. If it is unreasonable, and no other defences apply, indirect discrimination results.
>
> > ***The decision is extremely important as it means that cases of this type will need to be argued as indirect rather than direct discrimination.***
>
> This is significant, as it suggests that decisions that do not specifically target a protected attribute are likely to be upheld, as long as they are reasonable.

http://www.aar.com.au/pubs/pdf/wr/fowrnov03.pdf

In conclusion, people with autism have few rights and no effective legal protection. The law lets service providers deny them access to essential services on the basis of their behaviour. The Government and the community do not provide an essential service safety net for people with severe or profound disability due to autism. Specialist disability services are disappearing as rapidly as is politically expedient.

Most politicians ignore these issues. They wish the problems did not exist and avoid addressing them.

If you think ensuring the rights of people with autism, especially children, matters then please check it out. Since I am not a lawyer, you should first ask your friends who practice or know about the law. If they say I am right, please ask your political representatives to fix the problem (send them a copy of this with a letter asking them to tell you how they plan to fix it). Please let me know if I am wrong about this.

Bob Buckley
28/4/2007

Parent Survey, Monash Uni

Monash University - Parent Survey: Feasibility of Portable funding for students with disabilities
http://projects.education.monash.edu.au/disability-portable-funding/index.html

The survey can either be completed online or printed out and completed and sent in. (closes 25 May 2007)

For more information email Anne.Savige@education.monash.edu.au or for a hardcopy or call Anne on (03) 9905 0726.

Convenor's message

Dear A4 member

News from the political sphere is quite disappointing. Federal and state governments are squabbling over funding for disability services. The federal government inquiry found enormous need for additional disability services. Both sides are engaging in childish name-calling and finger-pointing.

On the federal side, I wrote to The Hon. Mal Brough MP, Minister for FaCSIA, on 7 August 2006 requesting a meeting about the last budget. You may recall that I wrote asking to discuss his respite initiative that targeted people with Intellectual Disability thereby excluding most people with ASD even though people with ASD have a much higher level of severe or profound disability. His EA responded on the 6 September 2006 saying she would try to find a date for a meeting. I have not heard from either of them since, despite several further requests for a meeting.

The Hon. Brough MP says he wants states to develop plans for increasing services and he expects them to work out the level of unmet need as the basis for their plans (see http://www.abc.net.au/pm/content/2007/s1888962.htm). Unfortunately the states have little capacity or capability to assess unmet need. The best sources of data and those with the ability to analyse the data are federal agencies that have been set up to collect and report on this data. The Hon. Brough MP has not made a case for the states to replicate the data collection and analysis capability of the various federal agencies that have data collection and reporting among their responsibilities.

Nor has the Hon. Brough MP met with community representatives, such as our A4 representatives, who can provide the information he wants.

The states could easily request the same information from the federal agencies that collect data. They could use the data to develop plans. They could account for the money they spend in an appropriate way ... rather than just reporting that they spent it, which is what they do at present.

Unfortunately, both sides are more interested in playing politics, while people with a disability, their families and associates, are caught in the middle.

Politicians say they appreciate and respect carers and the enormous contribution they make. If so, they have a very strange and especially ineffective way of showing it.

Christopher Pyne's responsibilities in government have changed again. I have not heard what is/will happening about his "responsibilities for autism".

You may have noticed the media coverage of the recent ASD prevalence study that found on average there 62 children with ASD in each 10,000 Australian children. Already this result has been misinterpreted. Please be aware that:

- some of the people aged 6 to 12 years have ASD that are yet to be diagnosed so the prevalence estimate should be expected to be low, and
- the study did not find this number of adults have autism … so the result cannot be extrapolated to the Australian population.

If government chooses to accept that the overall prevalence is 62 per 10,000 then it is much closer to the actual prevalence than the figures they were previously using. Using the prevalence of ASD in children to estimate adult prevalence could result in a massive improvement to adult services, but I believe such an error would backfire seriously in the long run.

I will write a number of separate articles on other key news items.

Regards
Bob Buckley
3/4/2007

A Letter from the Biennial Conference

Dear A4 members,

As many of you were not able to come to the Biennial autism conference I thought I'd give you my quick impressions. The topics presented are in the program (see http://www.astmanagement.com.au/autism7/). To get the full story, borrow the conference CDs from someone who went or from your state autism association.

The first day, Wednesday, started with the usual formalities: opening speeches and announcements. Keynote speakers on the day were Dr Catherine Lord, Dr Rita Jordan, Dr Brenda Smith Myles and Dr Tony Attwood.

Dr Lord talked about children who were thought to be on the spectrum when they were quite young and where they progressed to by their early to mid- teens. The outcomes were variable; with some (not many, but more than I would expect based on published research) who on a graph "cross the line" the line that represents "average functioning". (Note: a few young children who initially appear to have ASD go on to achieve developmental milestones at an above average rate as teenagers … but we must not use the terms "cured" or "recovered".) My impression was that children whose early diagnosis is not felt to be completely reliable (or where the child seems to have changed significantly) could be reviewed around 5 years of age.

Dr Jordan spoke expansively about how ASD challenges inclusive practices … whatever that is.

Dr Smith Myles gave excellent examples of "the hidden curriculum". She entertained the crowd with a woman's perspective on aspects of men's room social conventions; and a number of other challenges for the mostly female population teaching detailed social skills/rules to a mostly male student population.

Dr Attwood is collecting data. I will be very interested to see the outcomes.

Presentations in the rest of the day were in four streams. For me, the streaming was not ideal: too many things I'd most like to see clashed and at other times everything on was of lesser interest to me.

Dr Wray's presentation on gastrointestinal permeability and immune markers was especially interesting to me. This seems to be evidence offering scientific support to some theories around biochemical and dietary issues relating to ASD.

An annoyance for me is people using outdated ASD prevalence myths (like ASD prevalence of 1 in 1,000) … who then conclude that ASD prevalence of 5.3 per 1,000 in children whose hearing is impaired suggests there is a higher than average comorbidity of ASD with hearing impairment. Currently, ASD prevalence in Australia is 6.2 per 1,000 (see below) … which suggests to me that the difference (between 5.3 and 6.2 per 1,000) could be statistical variation or that a pre-existing diagnosis of hearing impairment might inhibit ASD diagnosis in some cases. It seems unlikely that having hearing impairment somehow reduces the risk of ASD.

Keynote speakers on the second day presented the latest Australian prevalence report. You may have seen mention of this in the media. The report's authors found 62 per 10,000 (1 in 160) children in the Australian population aged 6 to 12 years have an ASD. The authors did not attempt to estimate how many children in this age group have yet to be diagnosed with an ASD or may not take up Carer Allowance … or explain why the rate is lower in children aged 13 to 16 years.

A huge thanks to Dr Wray (a leading paediatrician) for pointing out that people with ASD and their parents will drive any improvement in government policy and/or service provision; researchers, clinicians, teachers and professionals do not drive change. *Let me reinforce this message. Please understand that as voters you have the power: You can tell politicians who represent you what you need and what you expect for your vote. They do not know what you want unless you tell them. Right now, with a federal election looming, is the best time to let your federal politicians know what you need from federal government. Every single letter makes a significant difference.*

Rita Jordan was entertaining again. And there was a panel …

At the end of the second day there was a research meeting/get together … but it was a closed meeting so I can only say that it happened.

I appreciated the keynote on bullying on the final day. The point for me is that our education settings still have lots to do just to "include" people on the spectrum who are fully functional academically … or better. Our education system(s) have so much more to do to accommodate people with more diverse needs. I understand this to mean that parents should be wary of unfunded "inclusion". When a school can't adequately fund and supervise its playground, what chance it can sufficiently resource the classroom?

A4 owes a big thanks to the ACT Autism Asperger Association Inc for hosting A4's brochures on their stand at the Conference.

Regards
Bob Buckley

From Federal Parliament

UN convention on the rights of persons with disabilities

A recent media reports says

> The Minister for Foreign Affairs, the Attorney General, and the Minister for Families, Community Services and Indigenous Affairs are pleased to announce that Australia will sign the United Nations *Convention on the Rights of Persons with Disabilities* …

http://www.facsia.gov.au/internet/minister3.nsf/content/un_conventions_30mar07.htm

Be advised … do not get your hopes up. Increasingly, Australian governments cynically sign and subsequently ignore these international treaties. The government's failure to address the appalling consequences for people with autism/ASD of the Purvis v. NSW Government in the High Court leave us with little hope that this will be any different.

In essence, the Federal Government signs these treaties but it fails to act on them. The government is supposed to include their provisions in Australian law. So far, Australian governments from both sides of politics refuse to include key provisions in our laws … so our vulnerable citizens do not have the protections the treaties are meant to provide. And when High Court decisions have been challenged in international forums the government rejects outcomes it did not like.

Currently, Australians with ASD have no discernible legal right to treatment, rehabilitation, education, employment, free speech, etc. under Australian law. And the government ignores legal results in international forums.

Contact with Minister for FaCSIA

A4 has been trying to meet the FaCSIA Minister for some considerable time.

On the 4/4, having heard various news reports about the CSTDA negotiations, I pressed for a meeting/telecon. with Mal Brough MP, FaCSIA Minister. He called me that evening and we had a frank discussion about the CSTDA and the role of federal government in disability services.

We talked about whether the states could assess the level of unmet need for services. I suggested that Commonwealth government agencies have the best data: the Australian Bureau of Statistics (ABS), the Australian Institute of Health and Welfare (AIHW) and Centrelink all have relevant data.

I supported his view that the states should be more transparent and accountable for their disability services.

I accept his apology for the delay in meeting an A4 representative.

He said he would ask a member of his staff to meet with me. We met and I provided an extensive range of information (there were a lot of issues pending since A4 had not seen a FaCSIA minister for some considerable time). I emphasised that ASD is distinct from Intellectual Disability. I said I regard restrictions on services to people with Intellectual Disability, when people with ASD would benefit from the service, is appalling discrimination.

I expect his staff will check the information I provided and brief the Minister. The key issues relating to FaCSIA are:

- Include ASD explicitly in the CSTDA definition of disability
- Ensure a range of effective early interventions are available immediately following diagnosis … I argued that since professionals cannot agree on which interventions are suitable for individual children, the parents should be able to decide what they regard to be best for their child.
- Provide effective disability services that support families, reducing stress and mental illness among people with ASD, their family and carers.
- Respite and accommodation (post-school generally) options for people with ASD

Hopefully, a new CSTDA will provide a better basis for services for people with ASD and their families and carers. Then we can work with government on improvements in the other crucial issues relating to people with ASD and their families.

Bottom of the Class

Bob Buckley, 19/3/2007

The House of Representatives Standing Committee on Education and Vocational Training released its report on the Inquiry into teacher education in February (see http://www.aph.gov.au/house/committee/evt/teachereduc/report.htm).

The report of the Inquiry is called *Top of the Class*. Do not bother to download it (the full 3.5Mb is at http://www.aph.gov.au/house/committee/evt/teachereduc/report/fullreport.pdf).

It is a deeply disappointing report. Most concerning is that the Terms of Reference specifically mention bullying and "children with special needs and/or disabilities" but these are the only mentions of these terms in the entire report. The only mention of "autism" or "Aspergers" is to acknowledge A4's submission.

Most of the recommendations are about money but a bigger problem is that the culture of education is unable to conduct research or even recognize evidence.

Autism costs society an estimated $3M per patient

Each individual with autism accrues about $3.2 million in costs to society over his or her lifetime, with lost productivity and adult care being the most expensive components, according to a report in the April issue of Archives of Pediatrics & Adolescent Medicine, a theme issue on autism spectrum disorders.

Autism costs society more than $35 billion in direct and indirect expenses each year, according to background information in the article. Relatively little is known about when these costs occur across the lifetime of an individual with autism.

Michael L. Ganz, M.S., Ph.D., Abt Associates Inc., Lexington, Mass., and Harvard School of Public Health, Boston, used data from the medical literature and from national surveys to estimate the direct medical and non-medical costs of autism, including prescription medications, adult care, special education and behavioral therapies. Approximate indirect costs, including lost productivity of both individuals with autism and their parents, were calculated by projecting average earnings and benefits at each age, adjusted for the fact that some autistic individuals can work in supported environments. Only costs directly linked to autism, and no medical or non-medical costs that would be incurred by individuals with or without autism, were included.

These costs were projected across the lifetime of a hypothetical group of individuals born in 2000 and diagnosed with autism in 2003. Costs estimates were broken down into age groups at five-year intervals, with the youngest group age 3 to 7 years and the oldest age 63 to 66 years.

"Direct medical costs are quite high for the first five years of life (average of around $35,000), start to decline substantially by age 8 years (around $6,000) and continue to decline through the end of life to around $1,000," Dr. Ganz writes. "Direct non-medical costs vary around $10,000 to approximately $16,000 during the first 20 years of life, peak in the 23- to 27-year age range (around $27,500) and then steadily decline to the end of life to around $8,000 in the last age group. Indirect costs also display a similar pattern, decreasing from around $43,000 in early life, peaking at ages 23 to 27 years (around $52,000) and declining through the end of life to $0."

Over an individual's life, lost productivity and other indirect costs make up 59.3 percent of total autism-related costs. Direct medical costs comprise 9.7 percent of total costs; the largest medical cost, behavioural therapy, accounts for 6.5 percent of total costs. Non-medical direct costs such as child care and home modifications comprise 31 percent of total lifetime costs.

Because these costs are incurred by different segments of society at different points in an autistic patient's life, a detailed understanding of these expenses could help planners, policymakers and families make decisions about autism care and treatment, Dr. Ganz notes. "Although autism is typically thought of as a disorder of childhood, its costs can be felt well into adulthood," he concludes. "These results may imply that physicians and other care professionals should consider recommending that parents of children with autism seek financial counselling to help plan for the transition into adulthood."

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(Arch Pediatric Adolesc Med. 2007;161:343-349. Available pre-embargo to the media at www.jamamedia.org.)

We are the force driving change

At the recent Biennial Conference Dr John Wray reminded audiences on several occasions that parents and families are the real driving force needed to achieve major political change for ASD in Australia.

Parent and families have the passion and the votes to pressure governments to act. In the USA, families and a few friends drove the Combating Autism Bill through the political system into law (see http://www.autismspeaks.org/press/combating_autism_act.php); and are pushing on with *the Expanding the Promise for Individuals with Autism Act* of 2007 (EPIAA), landmark legislation that would dramatically expand federal funding for life-long services for people with autism (see http://www.autismspeaks.org/press/expanding_promise_act.php). While advocacy like this may seem especially challenging, it is surprising what a few letters and persistent parents can do.

For example, Peter Hill, one of our members, is using his parent power to vigorously pursue issues relating to ASD-related research. Peter followed up on the government's claim that:

> *"The Australian Government invests almost $800,000 a year in autism research through the National Health and Medical Research Council,"*

(see http://www.health.gov.au/internet/ministers/publishing.nsf/Content/health-mediarel-yr2005-cp-pyn022.htm)

… a claim that turns out to be somewhat exaggerated. After four letters and some phone calls, Peter eventually got a meeting with government representatives, opposition representatives and his local member. Peter kindly took me with him to his meetings.

Peter used research done by Michael Ganz, Adjunct - Assistant Professor of Society, Human Development and Health at the Harvard school of Public Health (see http://www.eurekalert.org/pub_releases/2007-04/jaaj-acs032907.php), to put the case that ASD costs Australia $3.2 billion dollars every year. The government should spend much more than $800,000 each year on ASD-related research in order that funds are spent in the right areas.

As well as A4, Peter keeps in touch with AABASD and with the Australian Autism Research Alliance (AARA).

It was a good day of meetings. Both Peter and A4 have numerous leads to follow up.

On reflection of the day's events, parent power combined with good research can be a significant force for change.

Copies of Peter letters can be found at:

- http://www.a4.org.au/documents/PeterHillletters.doc (34K)
- http://www.a4.org.au/documents/PeterHillletters.pdf (22K)

Stabbing woman sent home

Annalise Walliker
January 19, 2007 12:00am
Article from: **Herald Sun**

http://www.news.com.au/heraldsun/story/0,21985,21084104-661,00.html

A WOMAN charged with stabbing her nine-year-old neighbour seven times has been allowed to return home on bail.

The woman, 29, attacked the boy with a pocket knife last Sunday just after 6.30pm, police said.

Department of Human Services authorities are now with the woman, who is autistic, and her family to assess if she should be moved following an emotional appeal from the boy's father.

The boy was stabbed three times in the chest, one narrowly missing his heart, three times in the back, puncturing one of his kidneys, received a wound to his hand and lost a litre of blood.

The woman lives across the road from the victim's Brunswick West home …

The woman was sent home after being deemed mentally unfit for questioning.

…

The story (if you want to read it and the profoundly ignorant comments from the community, follow the link) is an example of the one-sided sensational and shallow reporting we now expect from the media.

Before people comment on a story like this they should ask questions like:

- Where were the people supervising both the 26 year-old woman with severe untreated autism and the nine year old boy?
- Did the boy provoke a violent attack?

Yes, I have heard the argument that nothing justifies an attack such as this … but I am also concerned that the force of unrelenting verbal abuse and provocation on a person with communication and social skill disorders will inevitably provoke a reaction. The laws of physics and behaviour differ in that for behaviour the reaction is not constrained to equality.

The public response to the story shows the community is not ready for the government's policy of "inclusion devoid of support". This may be evidence that "inclusion devoid of support" is especially poor policy.

I sent the letter below to the federal Minister. I suggest Victorians send this letter or a similar letter to their politicians.

Parents also need to be aware that bad things can happen to young children who are not adequately supervised. Parents are responsible for ensuring their children are adequately supervised.

Governments are responsible for their failures in economic rationalism. And there is much more to this story than appears in the newspaper article.

A letter to politicians …

<your address>

<member's name>
<member's address>

Dear *<member's name>*

An appalling incident occurred recently in Victoria. Reports suggest a woman with autism stabbed a nine year-old boy who lived across the road from her. One article, with extensive and quite ignorant public comment, can be found at

http://www.news.com.au/heraldsun/story/0,21985,21084104-661,00.html

It appears from the media reports that both the woman with severe untreated autism and the nine year-old boy were unsupervised at the time of the stabbing.

I ask you to investigate:

1. Did the woman receive care and support funded through the CSTDA?
2. Did she have both an Individual Plan and a Case Manager as is expected by the National Disability Service Standards associated with the CSTDA?
3. Did the support and supervision meet her needs?
4. Did her Individual Plan identify a propensity for violence such as stabbing young boys? If not, why not?
5. Was she adequately supervised at the time of this stabbing?

Yours truly,
<your name & signature>

CSTDA letter

Currently, the federal and state/territory governments are supposed to be negotiating a new Commonwealth State and Territory Disability Agreement (CSTDA). This agreement is the basis for funding most of the non-education and non-health services for people with a disability in your state.

The recent Senate Inquiry found massive under-funding of disability services.

A4 members can send a letter like the following to their state disability minister about the coming CSTDA. Just copy the letter below and paste it into a new document; then change the letter any way you want … but please send something if you possibly can. Each letter sent really makes a difference.

The various Ministers and their addresses are:

Hon Katy Gallagher MLA Minister for Disability and Community Services ACT Legislative Assembly London Circuit Canberra ACT 2601 gallagher@act.gov.au	Hon Jay Weatherill MP Minister for Disability GPO Box 2269 ADELAIDE SA 5001 minister.weatherill@saugov.sa.gov.au
Hon Sheila Margaret McHale Minister for Disability Services 12th Floor Dumas House, 2 Havelock Street, West Perth WA 6005 sheila.mchale@dpc.wa.gov.au	Hon Kristina Keneally, MP Minister for Disability Services Level 36 Governor Macquarie Tower, 1 Farrer Place, SYDNEY NSW 2000 heffron@parliament.nsw.gov.au
Hon Delia Lawrie MLA Minister for Family and Community Services GPO Box 3146 Darwin NT 0801 minister.lawrie@nt.gov.au	Hon Gavin Jennings Minister for Community Services Level 22, 50 Lonsdale St Melbourne VIC 3002 gavin.jennings@parliament.vic.gov.au
Hon Larissa Giddings Minister for Health and Human Services Level 10, Executive Building 15 Murray Street Hobart TAS 7000 lara.giddings@parliament.tas.gov.au	Hon Warren Pitt MP Minister for Disability Services GPO Box 806 Brisbane QLD 4001 CandDS@ministerial.qld.gov.au

It is best to post your letter … and send a backup copy via email if you like.

You can also send a short email to Mal Brough (Mal.Brough.MP@aph.gov.au), the federal Minister for Family and Community Services, saying you are concerned about CSTDA negotiations. Don't forget to attach a copy of your letter to your state/territory Minister.

<*your address*>

<*your disability minister's name & address*>

Dear <*your minister's name*>,

Subject: **CSTDA, unmet need for disability services and autism**

Recent press reports say Mr Mal Brough MP, the federal Minister for FaCSIA, asked state and territory disability ministers in CSTDA discussion to estimate the level of unmet need for disability services.

Every 5 years, the Australian Bureau of Statistics (ABS) Survey of Disability, Ageing and Carers (SDAC) reports the number of people with a disability. The AIHW online data shows (see http://www.aihw.gov.au/cognos/cgi-bin/ppdscgi.exe?DC=Q&E=/Disabilities/all_20045) that of the 200,493 people who receive services funded under the CSTDA broken down under "Need for support in activities of daily life", there were 47,607 people "unable to do" things for themselves and 71,575 who could "sometimes" help themselves (and a further 42, 457 who received service though their ability to help themselves was "not stated"). At the very best, nationally one in eight people with a severe or profound disability get any assistance through the CSTDA. At least seven in each eight of the most disabled citizens get no disability service through the CSTDA.

The level of unmet need for disability services is a national disgrace.

If you are interested, you or your department may be able to get figures for <*your state*> and compare them with the national average.

My immediate concern is for people with Autism Spectrum Disorders (ASD). Remarkably, the definition of disability used in previous CSTDAs is unclear on whether it includes people with autism spectrum disorders. I urge you to ensure the definition of disability in the next CSTDA specifically includes Autism Spectrum Disorders.

The AIHW reports that people with ASD have the highest rate of severe and profound disability. The CSTDA and the <*your state*> government do not provide the services people with ASD need.

The federal Health Department recently issued a brochure on Early intervention for children with autism spectrum disorders: Guidelines for best practice that says children need "at least 20 hours per week over an extended period of at least two years" (page 4). A paper on autism in an Australian medical journal says …

> *"It is now widely accepted that between 15 and 25 hours of specific intervention is adequate, … Services available differ between areas, and in Australia there are no government-funded programs providing the recommended amounts of intervention."*

See http://www.mja.com.au/public/issues/182_07_040405/wra10330_fm.html

The minimal treatment and rehabilitation offered and provided for children with autism in <*your state*> comes nowhere near what experts recommend.

The recent Senate Inquiry into the CSTDA found massive deficiencies in services and support for people with a disability. The difficulties people with ASD experience are enormous and outcomes are profoundly inequitable, yet there is no sign <*your state*> government has any intention of addressing the issues and concerns about disability services for people with ASD.

The evidence shows the previous CSTDAs were agreements to massively under-service people with a disability. Will the CSTDA you negotiate be the same?

Yours truly,
<*your name & signature*>

Tribunal decides no treatment for autistic children

The ACT Discrimination Tribunal decided recently that autistic children have no right to treatment for their autism. The Tribunal said services for autism, a severe and pervasive disorder, is an issue of “resource allocation and government budget allocation decisions”; and deciding not to provide any treatment or rehabilitation appropriate for severe autism is not unfavourable to a child who is affected.

The Tribunal recently finalised seven (7) complaints about services for children with autism. Unfortunately, there are major problems with the Tribunal’s decision.

- The Tribunal rewrote the Applicant’s complaints instead of ruling on the complaints put before it.
- Legal counsel said
    - “we were unable to find a factual basis for some of the Tribunal’s findings”,
    - “we found reasoning in the decision was difficult to follow”,
    - “a number of findings appeared to be inconsistent” and
    - some findings “did not address the legislative criteria”.
- On average, the complaint process took over seven (7) years and the longest complaint took almost ten (10) years.

Mr Buckley, one of the Applicants, said “This shows the legal system in the ACT does not protect the rights of children with autism in particular, to treatment and rehabilitation … or meet the basic right to have legal matters processed fairly and in a timely fashion. This decision is a tragic blow to children with autism. The Government and the law are against them. Their families are left deeply disillusioned.”

The Australian Institute of Health and Welfare reports that children with autism have the highest rate of severe and profound disability. People with autism are among the nations most vulnerable citizens.

The Tribunal’s decision compounds the cruelty of the High Court decision (in *Purvis vs NSW*) that a person’s behaviour is not a part of their disability. Since autism is defined purely on the basis of behaviour, the High Court decided in effect that autism is not legally a disability under federal discrimination law.

Contrary to international law, children with autism in Australia have no right to services that are critical for them and their families.

“Governments at both the federal and state level should thoroughly review the way they treat people with autism and their families” Mr Buckley said. “Australia treats people with autism disgracefully. People with autism are denied legal protection. Few of them can access or afford the services they need.”

An annotated version of the Tribunal’s decision can be downloaded from http://www.bbuckley.com/files/ACTDiscTrib070405annotated.doc.

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: editor-at-a4.org.au
Editing: Juanita and Vicki
Reporting: we currently have vacancies in all states.

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

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