A4 Update
Autism Aspergers Advocacy Australia

February 2009 — Volume 7, Number 2

Debate over ASD/PDD increase

The Royal Australasian College of Physicians (RACP) released *A Consensus Approach for the Paediatrician's Role in the Diagnosis and Assessment of Autism Spectrum Disorders in Australia*[1]. In their opening paragraphs, the authors say

> Recent epidemiological research indicates an increased prevalence in autism spectrum disorders (ASD). There has been some debate about whether this increase is a result of broadening of the diagnostic concept, diagnostic substitution, greater awareness, the use of more reliable diagnostic tools, and/or a true rise in incidence possibly due to an environmental risk factor.

Their presentation casts doubt on whether a real increase has occurred or not … and favours the views that the observed increasing diagnoses are not due to a real increase in ASD prevalence. Material like this sustains the prejudice held by some politicians, bureaucrats and health professionals (and administrators) that the rise in ASD diagnosis is not "a true rise in incidence" so there is no real change in need in the community so they don't have to do anything about rising service needs.

The authors should tell us what "broadening of the diagnostic concept" they mean.

In relation to "epidemiological research" they cannot mean a shifting awareness in the community from *autism* to the broader *autism spectrum*. Obviously such an expansion would involve a larger number people but this is not the increased prevalence reported.

Is the RACP suggesting that the diagnostic criteria for specific conditions such as 299.00 Autistic Disorder/F84.0 Childhood Autism are broader than their DSM-III-R or ICD-9 criteria? Or do they mean the criteria for the whole group of Pervasive Developmental Disorders (including PDD-NOS, the diagnostic catch-all) are broader than before? The APA, when it changed how it described the criteria for these diagnoses, sought to avoid any such "broadening" effect.

There is little or no evidence that diagnostic criteria are broader now than in the past. By all accounts, the APA tried to improve or tighten the diagnostic criteria in going from the DSM-III-R to the DSM-IV.

> The DSM-IV criteria for autism attempted to keep the developmental framework and the broader conception of autism contained in DSM-III-R while at the same time improving its specificity and reintroducing several non-autistic PDD subtypes. The results from the large field trial indicated that the DSM-IV criteria (and the very similar ICD-10 criteria) have quite acceptable levels of sensitivity and specificity and can be reliably applied by clinicians.
>
> **Dr. Peter Szatmari, see** http://www.geocities.com/autismandpdd/thinking.htm

Increasing specificity and sensitivity of the criteria should have an opposite effect (a reduction) on the number of diagnoses.

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[1] see http://www.racp.edu.au/download.cfm?DownloadFile=72168A10-0DC8-5647-39D32208FE6D21AB, link on http://www.racp.edu.au/index.cfm?objectid=A4268489-2A57-5487-DEF14F15791C4F22.

Contents

Some people think that adding Asperger's Disorder/syndrome in the DSM-IV and the ICD-10 was a broadening of the diagnostic criteria. But anyone diagnosed with Asperger's Disorder/syndrome can be diagnosed with PDD-NOS using the DSM-III-R criteria. The addition of Asperger's labelling does not broaden the general criteria: it allows more specific diagnosis that can/should guide treatment and support.

Diagnostic criteria for PDD and the conditions in the ASD group have not broadened.

While the argument above says the criteria for diagnosing ASD are not now broader than they were in the past, there have been changes that increase the number of people diagnosed with a PDD/ASD. For example, the DSM-IV changed PDD (including ASD) from Axis-II to Axis-I. Suffice to say, such a change makes PDD and ASD more prominent in DSM-IV based diagnosis, making an enormous difference to how ASD is regarded. The DSM-IV criteria for Asperger's Disorder specifically mention employment prospects, an issue that was not mentioned in the DSM-III-R description. Previously, without such an explicit prompt many clinicians would not have considered such an issue when diagnosing a PDD.

In the past, there was little point to diagnosing an ASD as the diagnosis made little or no difference to the services and support provided. A person who presented with an intellectual disability was diagnosed with an intellectual disability and that was pretty much the end of it. For many, whether they also had an ASD was inconsequential.

Today, greater emphasis on PDD (perhaps because it is on Axis-I in the DSM-IV or maybe people believe now that a diagnosis brings benefits) means more people are diagnosed with both ASD/PDD and intellectual disability. This is not "diagnostic substitution". The person's ASD diagnosis is not substituted for intellectual disability … it is an additional rather than substituted diagnosis.

So what about "diagnostic substitution" … which purportedly describes people who are now diagnosed with ASD but were or would have been diagnosed with something else in the past? Recent papers on "diagnostic substitution" mostly approach the matter in a similar fashion. Without going through them all in detail, they seem to miss some relevant issues.

Substitution can occur when data collection or data analysis restricts or focuses on a singular (primary?) diagnosis for a person. Some proponents of the "diagnostic substitution" hypothesis use such data to support their hypothesis. For example, Shattuck concludes …

> Prevalence findings from special education data do not support the claim of an autism epidemic because the administrative prevalence figures for most states are well below epidemiological estimates. The growing administrative prevalence of

> autism from 1994 to 2003 was associated with corresponding declines in the usage of other diagnostic categories.[2]

Others observe

> In preparing this commentary, I have come to appreciate that even the “approachable” analysis of diagnostic substitution is a complex proposition. For example, Shattuck begins to address the notion of simultaneous substitution across several categories, a quite plausible scenario, but this is even more difficult to consider fully than the simple 1-for-1 substitution scenario I have been entertaining here. In the end, we may have to live with the fact that although administrative data suggest the potential for some diagnostic substitution, it remains difficult to confidently ascribe all of the observed autism prevalence increase to this particular phenomenon.[3]

Unsurprisingly, where diagnoses of both ASD and intellectual disability are recorded, the level of the “diagnostic substitution” reported is close to the rate described for children with both conditions.

The level of “diagnostic substitution” is unclear. Often, people with ASD and without intellectual disability experiences difficulty with learning … yet they are not described formally as having comorbid learning disorders. Typically their learning difficulties are regarded as part of their ASD.

Hopefully, we are well past “diagnostic substitution” of ASD for childhood schizophrenia.

The change is not always toward autism. Fragile X diagnosis mostly operates in the opposite direction: away from autism. There are notable declines in reported ASD as well as “diagnostic substitution” away from ASD in older age groups. An AIHW analysis of CSTDA data reported

> Of the service users aged 10–17 years with a primary disability of autism in 2003–04, 82% remained in that disability group in 2006–07, but a further 15% were reclassified as having a primary disability of intellectual disability.[4]

Mostly, these changes can be better described as improved diagnosis rather than “diagnostic substitution”.

There can be little doubt that “greater awareness” of ASD in the community contribute to the increased number of people diagnosed with ASD. An AIHW report says

> According to the 2003 ABS Survey of Disability, Ageing and Carers, an estimated 30,000 people had autism as a health condition (AIHW 2007 forthcoming). Of these, 24,100 (80%) also reported a severe or profound core activity limitation. This equates to a prevalence rate of 0.1% of the Australian population (AIHW 2005c). There is an increasing trend in the estimated number of people with autism—since 1998 the number of people with autism has doubled from 13,000

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[2] P. T. Shattuck (Apr 2006) *The Contribution of Diagnostic Substitution to the Growing Administrative Prevalence of Autism in US Special Education* PEDIATRICS Vol. 117 No. 4, pp. 1028-1037 (doi:10.1542/peds.2005-1516), see http://pediatrics.aappublications.org/cgi/content/abstract/117/4/1028

[3] C. J. Newschaffer (Apr 2006) *Investigating Diagnostic Substitution and Autism Prevalence Trends* PEDIATRICS Vol. 117, No. 4, p1437, see http://pediatrics.aappublications.org/cgi/reprint/117/4/1436.pdf

[4] AIHW (Oct 2008), *Disability support services 2006–07: National data on services provided under the Commonwealth State/Territory Disability Agreement*, Canberra, AIHW cat. no. DIS 52, p54 (see http://www.aihw.gov.au/publications/index.cfm/title/10654).

> people (including 12,400 as a severe or profound core activity limitation) (AIHW 2007). This trend is at least partly due to increased public awareness about autism spectrum disorders and a greater understanding by the community and medical practitioners in the diagnosis and/or reporting of autism.[5]

This "greater awareness" means some less acute presentations are diagnosed … but this is not a dominating cause of increased rates of ASD diagnosis. In the data cited by the AIHW above, the number of people with severe or profound core activity limitations almost doubled while the overall rate dropped from 95% to 80%.

In the past diagnosis of ASD usually depended on particularly profound symptoms, so people mostly accept "greater awareness" of ASD contributes to the increased number of people diagnosed with ASD. The increased diagnosis rate in adults is direct evidence of this effect: adults do not have new ASD, they have ASD that went undiagnosed.

Until the increased number of adults diagnosed with ASD reaches the prevalence observed among children, "diagnostic substitution" and "greater awareness" cannot explain entirely the increasing number of children diagnosed with ASD.

We should know how much change would result from using "more reliable diagnostic tools". Recent carefully conducted epidemiological (population) studies using the best available diagnostic tools gave results for prevalence that are similar to the prevalence figures observed in the Australian population. This suggests the diagnostic tools practitioners currently use may already be sufficiently reliable.

Here are some simple facts.

1. The observed incidence and prevalence of ASD has risen substantially in the last 10-20 years. Better knowledge and awareness, both in the community and in diagnostic practice, contributed to (but may not account for) the observed rise.
2. The observed rise in prevalence of ASD has been more noticeable among children.
3. The diagnosis rate for ASD among children is higher than the rate for adults.
4. The observed rise in prevalence of ASD is ongoing at this time.

Many questions remain. For example, is the underlying prevalence of ASD the same (or on the other hand different) among children and adults? If the underlying prevalence of ASD has risen, then what are the causes?

Many senior and very experienced clinicians have seen the number of children with profound autistic disorder increase significantly. They reject suggestions of past under-diagnosis for children profoundly affected by their ASD: they reject the implication of chronic under-diagnosis of profoundly disabling autism in the past. They observe a real increase in this "visible" subgroup. They expect there has been a similar real increase across the whole autism spectrum.

The key issue is that the number of people needing services for their ASD, whose lives can be improved substantially through access to appropriate services, is increasing significantly. Service provision fell behind and is falling further behind our knowledge of best practice service and support for people with ASD. We need to improve substantially access to appropriate services for people with ASD.

Bob Buckley, 16/2/2009

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[5] AIHW (Oct 2007), *Disability support services 2005–06: National data on services provided under the Commonwealth State/Territory Disability Agreement*, Canberra, AIHW cat. no. DIS 51, p50.

A response to the RACP diagnosis consensus

The Royal Australasian College of Physicians (RACP) document, *A Consensus Approach for the Paediatrician's Role in the Diagnosis and Assessment of Autism Spectrum Disorders in Australia*[6], should be applauded. It offers guidance that can improve diagnostic practice and outcomes for many children with ASD. Its very existence should increase recognition and awareness among physicians.

Following are suggestions for improving the document.

As is often the case, the document's guiding principles will not satisfy everyone. In particular people with ASD, not just children, benefit from accurate diagnosis and assessment.

Comments on other specific principles follow.

> #3 There is a wide range of available resources and models of practice in Australia and no clear consensus about a preferred method of assessment. A consistent, reliable, evidence-based process for the assessment of autism spectrum disorders is required.

It is not appropriate to accept the absence of consensus or preferred method in a principle. The RACP needs to choose or develop practice that provides accurate and clear diagnosis. People with ASD need accurate and reliable differential diagnosis that encompasses comorbid conditions.

> #4 Parents, carers and children with autism spectrum disorder require information about the nature, structure and reliability of the assessment process.

Principle #4 must include the person being diagnosed/assessed.

Principle #5 is a bunch of sub-principles …

- The first sub-principle conflicts with Stage 3 of the process described. *Diagnosis and Assessment of Autism Spectrum Disorders* needs to be about ASD, not "broadly applicable to any children with complex neurodevelopmental disorders". Perhaps they mean that they want diagnoses that accurately distinguish between neurodevelopmental disorders, so a full complement of relevant conditions need to be considered in the diagnosis process.
- As mentioned above, adults as well as children need accurate diagnosis, assessment, treatment and support.
- A key principle should be that delays in diagnosis do not delay access to crucial services such as early intervention … it is very one-sided to just "acknowledge that the assessment process may require a significant amount of time and expertise to complete" — we should also ensure that appropriate services are provided where there is a delay in diagnosis.

> #6 Two points: the person being diagnosed (the "patient"?) should also participate.; and putting carer (and "patient") participation last looks like an afterthought.

It is not enough to say at the very start "Acknowledge initial concerns regarding development and behaviour raised in the community by families, carers or service providers". The RACP should emphasise that physicians must respect from the outset the concerns that families and others raise in regard to a child's development. There are

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[6] see http://www.racp.edu.au/download.cfm?DownloadFile=72168A10-0DC8-5647-39D32208FE6D21AB, link on http://www.racp.edu.au/index.cfm?objectid=A4268489-2A57-5487-DEF14F15791C4F22.

still too many reports that physicians dismiss concerns raised over delays in a child's development.

It is not appropriate to advise and promote that physicians use their "clinical judgement" when many physicians lack relevant knowledge of and experience with ASD. It would be better to advise first that where there is any doubt, the matter is referred to specialists with the relevant expertise … provided this does not result in long delay. Secondly, the RACP could act to improve ASD expertise among physicians and develop the required clinical judgement.

The document promotes a model that provides a thorough assessment leading to the definitive diagnosis. This is not always the best model. Some children obviously meet the diagnostic criteria so diagnosis can be expedited.

For some children, diagnosis can be difficult even for experts. It may be apparent that the child needs some intervention, services and support before a diagnosis is finalised. Advice to physicians should promote processes giving early access to appropriate services in such cases.

The RACP document should better recognise that most children with ASD need comprehensive post-diagnostic assessment to guide their treatment, rehabilitation, services, support and education. For many, these assessments will need to be reviewed as the person with ASD progresses along their particular developmental pathway.

Hopefully, the RACP's document is the initial version of a living document.

Bob Buckley, 23/2/2009

Convenor's message

Dear A4 member,

I start with an apology to DMC for publishing the notes he sent for my information last month. I am sorry I misunderstood his intentions.

Have you looked at A4's website (http://a4.org.au/) recently? A goal of the new website is help members have a say. There is a link to 'create new account' in the user login area … on the left side). Please let us know via email if you have any trouble creating an account for yourself. Once you have an account you can post your own material on the website: you can comment in the online forums, add comments or further information to items on the website or even blog your own experiences. I hope people use our website to express opinions on ASD-related matters.

Are there issues you think the ASD community in Australia should discuss? Please raise them on the website. If you see ASD-related material in the media, then login and add it to the website. Once you login, there will be a link to 'create content' in the navigation box on the left of the screen. Click the link and decide what type of information (website content) to create.

Or if you read something on the website, you can add your comment (once you have logged in). Or you could ask a question and another member can answer.

As the content of the website is public, we expect that people treat each others with respect. Please recognise that ideas vary among A4 members and accept/expect there will be different opinions. A4's vision and mission will not be realised through internal discussion.

Increasingly, we will use the email addresses from the website for sending A4 material to members. Your can maintain your email and other relevant information on the website. This reduces the administrative burden needed to keep our mailing list and member information up to date.

Some of you will have seen FaHCSIA's Autism Advisors swinging into action and registrations for early intervention funding underway.

Implementation was relatively smooth until suddenly in mid January, the Government announced in the media an "Extra 1000 autistic kids to get funding"[7] and changed its eligibility rules.

The material in the media turns out to be pure spin. The Government will not like me saying so but it is important that A4 calls a spade a spade (and a shovel a shovel).

The story says "as many as 1000 more children, who would previously have been ineligible because of their attendance at school, could receive up to $12,000 this year." Previously, a child aged 6 years was eligible for early intervention funding if they did not attend school on a full-time basis. Now they are only eligible if they attend school on less than 80% of full-time and they meet other (as yet unclear, questionable and 'not for distribution') conditions. As each child is limited to $6,000 in a financial year, to access $12,000 they must access $6,000 in each half of the calendar year (and while they are still 6 years old).

So far, it looks like the new 80% school attendance rule and further conditions exclude people rather than increasing the number of eligible children. We are not aware that these changes help anyone access funded early intervention.

I hope people will understand that the new rules do not give the Autism Advisors discretion. The Government's rules and processes do not allow "special consideration by an autism adviser on a case-by-case basis" as the article claims.

Change is inevitable, but it can be done better. I am disappointed that the Government chose to

- make these changes without consultation,
- inform contractors and people running their programs via the media, and
- try to mislead clients and the public.

Overall the HCWA package is a major step forward. We appreciate the benefit people will get some from it. I applaud that it is up and running relatively quickly. Getting on with it provides the chance for everyone to learn and improve.

The federal approach is clearly better than the state governments who spend years on drawn-out "discussions" (arguments) over hypotheticals, plans to maintain their (inadequate) *status quo* and justification for their (inappropriate to ASD) ideology … with nothing visible in their budget, no discernible service improvement and as yet no visible prospect for improvement. Most state and territory governments do as little as they can get away with … and typically, their provisions for people with ASD and their families are profoundly inadequate.

Many families are accessing Early Intervention that was not available to them before.

However at this stage, I do not think FaHCSIA's Early Intervention Service Provider Panel is achieving what children with ASD need. Many families still cannot access the type of early intervention and the intensity of service their child needs. Choice is often limited: for example, there is only one panel provider in the ACT.

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[7] see http://www.theaustralian.news.com.au/story/0,25197,24994058-2702,00.html

In some instances, state and federally funded therapy and early intervention are separate and cannot be integrated. This is obviously less than ideal. It wastes resources and fails to deliver crucial outcomes.

The DEEWR element of HCWA provides basic information for teachers who are including students in mainstream settings. It cannot provide the comprehensive skills in specialised pedagogy that many students with ASD need to accelerate their learning sufficient to achieve equitable outcomes in education.

None of the elements of the HCWA package address the clinical needs of school age children with ASD effectively.

The routine refusal of governments to address behavioural issues results in many schools excluding their students with ASD thereby denying those students access to effective education. Typically, the exclusion of students with ASD are not reported or recorded. Governments ignore these exclusions and sweep this issue under the carpet (with support from the High Court in the form of the Purvis decision).

Students with ASD have clinically significant social impairment. Untreated, their social dysfunction routinely results in severe anxiety, depression, challenging behaviours, etc. This is a major mental health issue and a serious impediment to equitable education outcomes. Yet no element of the HCWA package addresses these issues.

In most (if not all) states, students with ASD whose communication is impaired find their access to therapy, treatment and rehabilitations is pretty-much terminated when they enter fulltime school. It is as if bureaucrats and their political masters expect teachers to meet the child’s clinical needs … which role teachers are clearly unable to fulfil.

If our wider community wants better long-term outcomes for people with ASD, our governments and policy-makers need to appreciate the nature of ASD and how the needs of people with ASD can be met. They need to understand that, just as people cannot “catch” autism, people with autism cannot “catch” normal functioning no matter how much contact they have with normal people.

At its announcement, we were told the HCWA package was just a beginning. I am keen to see what comes next.

Please be aware that these are my opinions: they are just one of the opinions of A4’s membership. It would be good to see other A4 members adding their views on the A4 website or writing for our Updates. Remember A4 represents the range of views of its members: if members have views that cannot be unified, then it represents the different views … but it needs its members to express those different views to politicians and decision makers, its target audience.

Do you want to help get A4’s message(s) to both federal and state government? A4 needs people to help decide and express its messages and to be a part of sending its messages to governments, service providers and the community generally. Enthusiasm is what we need most. Please email me (cnvnr@a4.org.au) if you want to help and can find some time for A4 in your life.

Regards
Bob Buckley
A4 Convenor

National Press Club of Australia

The Hon Bill Shorten MP

Wednesday 01, April 2009

Parliamentary Secretary for Disability and Children's Services

Registration Form:
http://www.npc.org.au/assets/files/documents/speakers/BillShorten010409.pdf

Broadcast live on ABC1 at 12.30pm. Repeat at 3.25am.

The Rudd Government has put the social inclusion of disadvantaged groups – including people with disability – at the core of its vision for Australia.

Public recognition is growing that Australians with severe disability and their family carers deserve better support.

The Rudd Government has vested responsibility for delivering on its plans for disability services in one of its new team, Parliamentary Secretary Bill Shorten.

The Rudd Government has promised to deliver a National Disability Strategy and a National Disability and Mental Health Employment Strategy, both of which will require the cooperation of State and Territory governments.

It has set up an inquiry into how to increase investment into the chronically under-funded disability sector and it has promised to revamp the Commonwealth State/Territory Disability Agreement, the national policy and funding framework for services to 220,000 Australians with severe disability.

ASD in the news

Brains of autistic slower to react to sounds: study

http://www.reuters.com/article/scienceNews/idUSTRE4B00PI20081201

By Andrew Stern

CHICAGO (Reuters) - The brains of autistic children react to sounds a fraction of a second slower than those of normal children, which may help explain the communication problems associated with autism, researchers said on Monday.

"What this does is it provides strong supporting evidence for the emerging theory that autism is a problem of connectivity in the brain," said Timothy Roberts, vice chairman of research in the Department of Radiology at Children's Hospital of Philadelphia.

Roberts and his colleagues had 30 autistic children age 6 to 15 listen to a battery of sounds and syllables while monitoring the tiny magnetic fields produced by the brain's electrical impulses.

The test employed a technique, called magnetoencephalography (MEG), in which a helmet-like device is used to detect and locate brain activity. Only around one hundred devices exist that can monitor the tiny magnetic fields, Roberts said in a telephone interview.

In comparison to the tenth of a second response time in the brains of normal children in the study, the autistic children's brains were anywhere from 20 percent to 50 percent slower to react.

Since a single syllable in a multisyllable word might take less than one-quarter of a second to say, Roberts said 1/20th of a second extra delay in the response time of the brains of autistic children may hamper their ability to comprehend.

"There could be abnormal routing or a lack of connectivity in the brain," he said in a telephone interview. "It may be like a highway with traffic making it hard to get through."

"We think this (delay) is a signature or a biomarker that could be used to stratify autism patients," since autism is a spectrum of disorders that afflicts people to vastly different degrees, he said.

FEWER CONNECTIONS

Microscopic examination of the brain tissue of people with autism has shown there may be fewer connections between their brain cells, said Roberts, who presented his findings at a meeting of the Radiological Society of North America.

Brain scans performed by the more frequently used magnetic resonance imaging or computed tomography are not detailed enough to detect such microscopic differences in brain cell connections. Such scans have not found structural or size differences between autistic and normal brains.

Autism, which is characterized by difficulty interacting with others and sometimes repetitive behaviors, occurs in about one in 150 U.S. children, a rate that has climbed since the 1980s.

Children are usually diagnosed with autism only after they reach age 2 years or older and Roberts said the hope is that MEG could diagnose children as young as 1 year, so therapy could begin earlier and perhaps be monitored to evaluate the results on the brain.

MEG can cost roughly $400 an hour to perform, but it is harmless and could become less expensive if more devices were available. MEG is used currently to help locate brain tumors and to diagnose epilepsy.

Roberts foresees MEG being employed to examine people with attention deficit disorder and other mental problems.

He said it may also provide researchers with more clues to the causes of autism and help solve the dilemma of what is hereditary and what is environmental about the condition.

Disabled student takes state to court

http://www.theage.com.au/national/disabled-student-takes-state-to-court-20081230-77f2.html

Miki Perkins, December 31, 2008

A VICTORIAN teenager with multiple disabilities is suing the Education Department for discrimination, claiming it failed to provide him with a full-time education.

Alex Walker, 13, and his mother, Paige Walker, have launched legal action against the State of Victoria, claiming he was not allowed to attend school full-time, was banned from school excursions and forced to return home for lunch because funding was not available for a teaching aide.

Struggling: Alex Walker, 13. Photo: *James Knowler*

They also say he was not allowed to travel on the school bus, forcing Mrs Walker to drive 400 kilometres each week to take her son to school.

Alex, who lives with his family in the west Victorian town of Branxholme, has a number of disabilities, including Asperger's syndrome — an autism spectrum disorder — dyslexia and attention deficit disorder.

Access Law, acting for the family, will tell the Federal Court in February that at the age of five Alex had a "bright" IQ of 120, but this has now dropped below 100.

His mother said yesterday Alex had the spelling ability of a seven-year-old, wrote in a mixture of capital and lower-case letters, was far behind in maths and could only "skim read". She claims discrimination has led to a drop in his IQ, frustration, anxiety and a loss of educational opportunities. "As for a social circle, he doesn't really have one," she said.

Because of his disabilities, particularly Asperger's syndrome, which is characterised by difficulty in social interactions, Alex resorts to swearing when under stress. His mother said teachers unfamiliar with the disability could misconstrue this as bullying or controlling behaviour.

Anti-discrimination consultant Julie Phillips said there were many students similar to Alex who were refused full-time school attendance because of a lack of funds.

"Victoria has a long way to go in offering equal access to education for students with disabilities," Ms Phillips said.

When Alex started primary school in 2001 at the Branxholme-Wallacedale Community School, the school failed to apply for funding from the Education Department for an aide, his mother said.

When Alex started secondary school in 2007, he was forced to move between an independent high school, distance education and home schooling because the department would not fund support for his full-time education, Mrs Walker said.

When he finally got funding, Alex was only able to go part-time to Baimbridge College, in Hamilton, and was not allowed to travel on the school bus.

Last year, the Government was ordered to pay more than $80,000 compensation to 16-year-old student Rebekah Turner, who has a severe language disorder and learning disability, when it was found that the Education Department had failed to provide classroom help for her.

The Government has since sought leave to appeal against the decision.

The department, which will contest Alex Walker's allegations, said it would be inappropriate to comment while the matter was before the courts.

A spokesman said that since 1999, expenditure for students with additional learning needs had increased by 86 per cent.

Children of the rainbow need support

http://www.theage.com.au/opinion/children-of-the-rainbow-need-support-20090106-7b4s.html

Ebru Yaman, January 7, 2009

YOU don't often see Asperger's syndrome as the sympathetic hook to a storyline, let alone see mainstream treatment of the rocking, hand-flapping, head-banging end of the autism spectrum, so for parents with a child who fits within this spectrum — and that would be one in 150 of our children going by recent statistics — *The Magnificent 7*, shown on ABC television last Sunday may have been a small relief.

Maggi, played by Helena Bonham-Carter, has three girls she refers to as "normal" and four boys all along the autism spectrum. She likes the term, she tells another character, because it reminds her of a "rainbow … a prism of colour".

This story of four such boys in one family hints at theories of the genetic underpinnings of autism but the idea isn't explored in this telemovie — probably just as well as such theories are the basis of contentious scientific research.

While the children that Hans Asperger dubbed his "little professors" in the 1940s displayed some classic autistic traits, they differed enough for the group he studied — children who had in common often astonishing memories and intense, usually narrow, specialist interests — to eventually take on Asperger's name to define a subset of autism. There were several defining features of this cohort, the most important being the possession of an average and often well-above-average IQ.

First identified in the 1940s, Asperger's syndrome did not gain wide recognition until the 1980s, when British psychiatrist, academic and autism specialist Lorna Wing revisited Aspsperger's observations. It was another decade or so before the condition, essentially neurobiological, made its way into the bible of psychiatric disorders, *The Diagnostic and Statistical Manual of Mental Disorders*, published by the American Psychiatric Association.

I didn't become familiar with what Asperger's involved until two years ago when my son was eight. After six years of noting the raised eyebrows at his unusual speech development, his propensity for lining up toys, his delayed toilet training and his narrow, extreme interests (he once spent three entire days in role play as a lizard), I had become accustomed to protecting this clever, beautiful child from labels.

Cal's sense of humour was so sophisticated — he was, and is, just so funny — that I could not bear, would not tolerate the notion of developmental delay or learning difficulty. Learn? He inhaled facts and he never forgot them, although only when his own interests were stimulated. Those interests were reptiles (including dinosaurs), amphibians and then, down the list, animals in general.

Maybe I should have twigged when he spent hours organising his collection of plastic animal figures or when his food selections became so particular, but the term Asperger's meant nothing to me.

It took an exceptional year 2 teacher and a gut-wrenching quest for Asperger's specialists to lead us to a starting point for understanding our son and the beginning of helping him find the vocabulary he needs to negotiate the world.

Diagnosis can provide some answers where before there were only questions and anxiety. It can also help with a way to streamline the endless, labyrinthine bureaucracy of child services. In this case it allowed me to make a beeline for the services he needed (although paid for privately — the public waiting lists are horrendous), blocking out the white noise of inappropriate armchair assessments.

He is, as it turns out both classically and mildly autistic, and a text-book case (as much as there can be one) of Asperger's syndrome. He understands the world literally, he struggles with idiom, with non-verbal cues and with empathy — even though he can give the best hugs I have ever known. He needs a mainstream school but one with a degree of sympathy and understanding for his beautiful, skewed outlook.

I have been able to find only one such school in my home city, and that is in the independent system. It is a massive financial commitment but a small cost when measured up against the reality of fears I have for him finding his own way in a school where teachers have on average 1.5 hours of professional development in the area of autism.

I imagine there are many parents in my situation and many without the luxury of choice. What do they do? These children are the most prone to bullying in the schoolyard because of their lack of artifice and their sheer inability to tell a fib.

Then there are the absent skills that can be learned, but they must be deliberately learned — to ask how a person is upon greeting, to answer a question even if it doesn't interest him, and to learn that when someone is, for example, tapping their fingers against a table and grimacing they might be agitated. He has had to learn that when a person's face is wet it's because they're sad. And among all this his love is the purest, the fiercest, I have ever known.

Last year the Federal Government allowed a small amount of money — about $2000 for a family — to contribute towards specialist autistic services for children to the age of 16. But I estimate my family has spent $15,000 on speech therapy, occupational therapy, and other services in the past 2½ years alone.

I would like us all to talk more about autism, about Asperger's, about the place these people take in our society and about the many undiagnosable conditions that sit along this spectrum because for too long they have remained unmentioned.

Ebru Yaman is a former education journalist and the mother of two children, one of whom has Asperger's syndrome.

Major's mission: help his best friend to the Max

http://www.canberratimes.com.au/news/local/news/general/majors-mission-help-his-best-friend-to-the-max/1425511.aspx

BY NYSSA SKILTON, MEDICAL AND TECHNOLOGY REPORTER, 5/02/2009

Spontaneity and friends are things to be avoided in Max Gurney's world.

The nine-year-old, of Watson, has autism and prefers a strict routine and his own company; people are too complicated for friendships.

But now a dachshund called Major is starting to enter his world.

The Gurney family bought Major from the pound in October for Max, and mother Rachel said she had already seen big changes in her son.

''He's very attached to him already,'' Mrs Gurney said.

''People talk to animals with affection. Most people will see an animal and give them a nice greeting, and what that does is it shows children with autism how to greet and how to interact.

''I think the dog has really got a sixth sense. He just knows what Max is about.''

A new study at Monash University in Melbourne will explore how man's best friend may change the world of a child with autism.

There is a growing number of organisations worldwide training dogs to assist children with autism. Many have been inspired by Nuala Gardner's book, A Friend Like Henry, which tells the story of how Gardner's son, Dale, conquered autism with help from a golden retriever.

School of psychology senior lecturer Pauleen Bennett said academics wanted to scientifically evaluate the extraordinary claims of the benefits of dogs for children with autism. ''It's about trying to bring science into something that a whole lot of people think is a really good idea,'' Dr Bennett said.

"Dogs are really special. They have a different relationship with people than other animals do."

The $40,000 study will take place over the next three years. Researchers will work with Bendigo-based Righteous Pups Australia, a non-profit organisation, which trains assistance dogs for people with disabilities. The organisation is the only one of its kind in Australia to train assistance dogs for children with autism.

It trains these dogs, predominantly Labradors, in companionship and behaving appropriately in public spaces. It also teaches the dogs to interrupt repetitive behaviour by gently nuzzling or using their paw to distract a child. Righteous Pups began training assistance dogs for children with autism in 2005 and has trained and established nine dogs with families across Australia.

Managing director Jo Baker said the demand for these autism assistance dogs was enormous.

There were more than 200 families on the waiting list for the dogs and they hoped to eventually train 100 dogs a year to keep up with demand.

The dogs, provided free to families, cost almost $30,000 to train.

But, Ms Baker said, the results had been phenomenal.

She said one 14-year old girl, who had never shown interest in hugging or kissing her mother, showered her dog in affection on the first day of meeting the dog. She later brought her mother to tears when she spontaneously kissed her.

Another young boy could not go to the supermarket because he would run away and couldn't stand to be touched. But walking with his assistance dog, he was happy to follow his mother along the aisles.

"For our team, there is nothing more powerful than seeing this dog be able to invade the world of a child with autism, where we humans can't seem to work it out," Ms Baker said.

"A dog couldn't care less if you've got four toes or six heads. As long as you treat that dog well, they'll love you forever and I think that's the magic."

More information about Righteous Pups Australia can be found at righteouspups.org.au

Letters

if I was conceived today I'd be aborted as defective

If this isn't news to the A4 community ...
http://www.guardian.co.uk/lifeandstyle/2009/jan/12/autism-screening-health

Gordon Drennan

12th January 2009

Increasingly I am finding that when you say Asperger's Syndrome people think you are talking about someone who is violent, abusive and totally out of control. Somewhere along the way the personality type that Asperger first noticed has been forgotten. Child psychologists are very different sort of people to those who have got Aspergers, and I'm sure a lot of them are totally unable to understand it. Once they got involved they took it and turned it into something they could own: childhood behavioural problems. And now anyone who has significant childhood behavioural problems is being diagnosed as having Aspergers, and anyone who doesn't isn't. A diagnosis has become how much of a problem you are (or were) to your parents and teachers, not how much of a problem you have with the world. And support organisations have become support organisation for parents and teachers. Not those who actually have it, and have to live with it beyond childhood. For example point a potential employer who has no idea of what Aspergers is at the web sites of the state Autism/Aspergers and you find a relentlessly negative definition with absolutely no positives that'd turn them off employing you. These organisations have become the problem, not the solution, by saying the person with Aspergers is the problem.

Perhaps those of us who have Aspergers need to take Aspergers back, or maybe come up with a new name, like, say, the Bill Gates Sydrome.

Gordon Drennan

> *Thank you for your comments. Both personally and as A4 Convenor, I have spoken out about instances of prejudice and misconception against Asperger's … and ASD generally. Hopefully, A4 helps people with ASD including Asperger's, as well as families and carers, have their say in the broader community.*
>
> *I urge people to write factual (avoid emotion) directly to the editors and owners of media that publish negative, inaccurate of inappropriate images. Past A4 Updates include some examples of what can be said.*
>
> *Governments do not fund the state autism associations to provide employment services. This may be why their websites do not cater for employment issues. I think most of them would be interested in how they could contribute better to employment outcomes for people with Asperger's. If you provide them (or us) with material you feel is appropriate, they are more likely to put it on their website.*
>
> *Regards*
> *Bob*

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.

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