

## **Studies show increase in Autism cases**

Australian officials currently estimate that about one in 160 children are diagnosed with autism, but findings from two new studies suggest it is much more common.

It is not clear whether autism itself is on the rise, or whether better diagnosis is inflating the figures.

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Researchers from Melbourne's La Trobe University studied 20,000 children as they grew from infants to toddlers.

They trained baby health nurses to pick up early signs of autism.

Dr Cheryl Dissanayake is one of the lead researchers.

"So what we're finding from the SACS study is that one in 119 children are meeting criteria for an autism spectrum disorder at the age of two years," she said.

"These data are in accordance with the data coming out of the UK."

### **'One in 100'**

Professor Margot Prior says a second independent study from the university found the figure was close to one in 100.

"Well we had 19 autistic children in a sample of 1,900. So that's one in a 100. So again, we believe that the prevalence is certainly greater for whatever reason," she said.

"And of course this is a population, you know, a non-clinical sample, just from the population out there."

It is still unclear whether there are more cases of autism or whether doctors are just more aware of the condition and likely to pick it up.

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*for more see*

- <http://www.abc.net.au/news/stories/2009/07/23/2634744.htm>
- <http://au.news.yahoo.com/a/-/australian-news/5746839/studies-show-increase-in-autism-cases/> *and*
- <http://www.abc.net.au/pm/content/2008/s2634743.htm>

## Contents

Studies show increase in Autism cases.....	1
Convenor’s message.....	2
Disabled take charge.....	5
Kevin Rudd taps into concerns on autism.....	6
Researchers See Recovery From Autism.....	6
American Psychiatric Association (APA).....	9
Neurodevelopmental Disorders Work Group.....	9
Report of the DSM-V Neurodevelopmental Disorders Work Group.....	10
Clarification of the definition of PDD-NOS.....	12
The curious incident of the straight-A student.....	13
A savvy savant finds his voice.....	14
Letters.....	14
A4 Contacts.....	16

## Convenor’s message

Dear A4 member,

Advocacy and lobbying is the primary purpose of A4. A4 needs its members to say what they want Australian governments to do to improve outcomes for people with ASD. A4 is asking you because professionals in the field of ASD so far have not articulated a comprehensive approach to the treatment, service and support of people with ASD to government. Nor do professionals in Australia have sufficient political clout (or passion) to get Australian governments to act. People with ASD and their families need to push governments for services that result in better outcomes.

A4 has current email addresses for over 1,200 members. Nationally this is about 1 current A4 member for each 20 or 30 people with ASD. This is remarkably good representation for such a group.

At this time, A4 is reorganising. It seems most members just want the Committee to “get on with **it**”. But the challenge to “making **it** happen” is deciding just what “it” is. A4 activities (what A4 does) include:

- Systemic advocacy and lobbying;
- Publishing and distributing the A4 Updates;
- Operating the A4 website (<http://a4.org.au/a4>); and
- Less obviously, running the A4 organisation and general autism/ASD awareness.

All A4 activity depends on volunteers. Hopefully, our volunteer group achieves more than would be achieved by the individuals operating alone. However, when the number of volunteers gets too small, some A4 activities suffer. Some things do not get done, or are not done as well as we would like.

Currently, A4 is trying to expand the volunteer group involved in A4 activities so that A4 can do a better job. Hopefully, A4 members understand that complaints about what A4 does or how it does it just do not help. If you want to help, please contact the Convenor ([cnvnr@a4.org.au](mailto:cnvnr@a4.org.au)) and be prepared to join in. Members will be more effective when they themselves work to achieve their goals ... the existing A4 organisation may be able to help them. The focus must be on doing stuff. If the volunteers in A4 are not addressing your concerns, they probably need your help. So get involved.

Even if you cannot help, A4 is interested in why you signed up as an A4 member; and especially in how A4 can best express your needs and expectations. Over the next few

months I anticipate A4 will ask its members what they want. Please think about your issue and what you need, and tell us about it so A4 can pass the message on.

A4 is trying to make its website easy for members to access and use. If you do not have an account, please go to the website and create one (click on the link and fill in as much information as you are comfortable providing). If you type (or paste) your email address correctly, the website will send you an email telling you your password. You can login, then go to 'my account' and make your password what you prefer.

Once you login to the A4 website, it is very easy to vote in a member poll. The current poll is an example. We just want to know how members feel about the style of A4 Updates. A significant amount of work goes into producing the A4 Updates ... and they seem to be a significant reason why people join A4. Voting shows the team that you value their efforts. Please just vote ... or make a comment. *Note: this newsletter uses the "spectrum style" preferred by the majority of voters at the time it is being prepared.*

The A4 website lets members raise issues and concerns in the forum section of the website. Please use it to raise and discuss issues relating to autism/ASD and our government ... and the organisation and operation of A4.

Now, onto other news ...

Recent reports from Victoria (see above) suggest higher rates of ASD than have been previously reported. FaHCSIA has also shown the Autism Advisors data on Carer Allowance recipients that indicate substantial rises in the number of young children diagnosed with ASD, with the biggest increase over the last 4 years in Victoria. I will have more to say about this in coming months.

The American Psychiatric Association is working on the next version of the Diagnostic and Statistical Manual of Mental Disorders 5<sup>th</sup> edition, expected to be called the DSM-V (see below). While it is "interesting", the changes are unlikely to have much effect on our daily lives.

One of the issues being considered is whether ASD are always life-long. There has been a recent flurry of media in USA around the possibility that some people with autism/ASD apparently experience a form of "recovery" (see below) or "optimal outcomes", a term some prefer.

Not everyone is happy with efforts to "recover" people from ASD or even reduce the effects of autism/ASD. A Newsweek article, "*Erasing Autism*" (see <http://www.newsweek.com/id/197813>), says ...

... Ari Ne'eman is 21 years old and has Asperger syndrome, a high-functioning diagnosis on the wide-ranging autism spectrum. ... He doesn't want anybody to mess with or, God forbid, cure his Asperger's. It's who he is, who he's always been.

...

But the new genetic advances concern Ne'eman. He doesn't believe autism can be, or should be, cured. His ultimate fear is this: a prenatal test for autism, leading to "eugenic elimination." If a test is developed one day, it will be used, he says. And that means people like him might cease to exist.

Suggesting "eugenic elimination" as the purpose of genetic research is naïve at best, at worst it is offensive to genetic researchers. Despite significant efforts, the underlying nature of autism remains pretty much a mystery. Increasingly, research is looking to brain biochemistry to explain ASD and future understanding likely depends on understanding the genetics that affect the biochemistry.

It is unclear what Ne'eman means by “to mess with or ... cure his Asperger's.” His simple media message makes his perspective look very “black and white” or over simplistic. The article goes on to say ...

Ne'eman battles a strange kind of image problem: his critics accuse him of not really being autistic. His mother, Rina, is particularly sensitive about this. "People who see Ari today have no idea where he's been," she says. As a young child, Ne'eman was verbally precocious but socially challenged. "I didn't understand the people around me, and they didn't understand me," he says. He was bullied and ostracized—back then he didn't look at people; he flapped his hands and paced incessantly (he still does both today); he brought newspapers to elementary school as leisure reading. "I think the word 'freak' may have come up," he says. He was, at one point, segregated from his peers in a special-ed school. That led to struggles with depression and anxiety so severe he would pick at his face until it bled. I asked Ne'eman how he manages all the professional mingling he does today. Small talk makes him uncomfortable, but he's learned to play along. Still, none of it is easy. "You come out of a meeting and you've put on a mask, which involves looking people in the eye, using certain mannerisms, certain phrases," he says. "Even if you learn to do it in a very seamless sort of way, you're still putting on an act. It's a very exhausting act."

...

He remembers being taught in social-skills training that when people are happy they smile with all their teeth, and when they're sad they wear exaggerated frowns. "I was always wondering, 'Why is everybody around me neither happy or sad? They don't have emotions'," he says. When you're autistic, social interaction can be like a foreign language: no matter how fluent you become, you're never a native speaker. Katie Miller, a fellow activist, jokes that "Ari is the only autistic we know whose special interest and talent lies in networking." But, she says, "it didn't come naturally. He's learned it the way everybody else learns algebra." Ne'eman has a way of taming the stress he feels: he wears a tie because it puts a soothing pressure on his neck. "It's a good way of calming my anxiety," he says.

By all accounts, Ari Ne'eman is an example of “best outcomes”. The account shows “social-skills training” was used “to mess with ... his Asperger's”: and he learned some of his key skills “the way everybody else learns algebra”. We all hope for happy outcomes for people with ASD; outcomes where people with ASD like who they are and their place in their community and where their community appreciates them. I think most people want these results with as little *messing with their Asperger's* as possible.

I applaud increasing our inclusive community: where as many people as possible are part of their community and we value, even celebrate, their “differences”. Changing our community so fewer people are regarded as dysfunctional or disorders is a great outcome; the best way of all to recover or cure ASD.

I do not know Ne'eman: I have not met him or even seen a photo of him. But I expect we have similar personalities. People do not regard me as “normal”. I am proud of my “differences” and I value them. I manage aspects of my personality that can cause others discomfort. Like Ne'eman, I am self-confident and have some networking skill. Unlike Ne'eman, I am nearly three times his age and it is likely I am on the spectrum but I have not been formally diagnosed with ASD.

People like Ne'eman (and me?) are not typical of those on the spectrum. In my view, assuming people with ASD can all learn to manage or overcome their dysfunction and disorder is a big mistake.

Even in an ideal world, he may not resemble the majority of people with an ASD. Many people with ASD do not learn to manage the challenging aspects and to value other aspects of their condition. Many people do not value “difference”: they just want to be normal. Many high-functioning people with ASD do not learn sufficiently functional social skills; so they are not happy being “who they are” and they often want to reduce or eliminate their ASD. Their views vary and my experience has taught me to respect their varying views.

I cannot see how Ari Ne'eman's experience and expressed views (and those of his followers) relate to situations and experiences where an outcome is at the other extreme (see *Luke deserves so much more* <http://www.news.com.au/heraldsun/story/0,21985,25665017-2862,00.html>, [http://www.parliament.vic.gov.au/fcdc/inquiries/support\\_accommodation/Submissions%20posted%20online/Carers%20Submission%20Posted%20Online/90%20%20MODRA,%20Mark%20&%20Luke.pdf](http://www.parliament.vic.gov.au/fcdc/inquiries/support_accommodation/Submissions%20posted%20online/Carers%20Submission%20Posted%20Online/90%20%20MODRA,%20Mark%20&%20Luke.pdf) and <http://www.news.com.au/couriermail/story/0,23739,25665018-2862,00.html>).

A4 tries to recognise and represent the range of views associated with ASD.

The needs of people with ASD extend beyond creating a more inclusive community. Many people need ASD-specific services that are not available, and mostly not even on the Government's or the community's agenda.

Many A4 members are dissatisfied with the government's limited ASD-related services, especially the lack of services for people with ASD over 6 years of age. The ASD community needs to offer more practical (and politically acceptable) suggestions about what the government should do to improve outcomes for people with ASD.

While the government's *Helping Children with Autism* package offers some teacher and parent training and support, and a few Medicare items, few people regard this as sufficient for school age children. What should the Government do to meet the needs of people with ASD, their families and other associates?

Regards  
Bob Buckley

28/7/2009

## **Disabled take charge**

MANY umpire organisations have disabled officials in their ranks, but the Geelong Football Umpires League broke new ground on Saturday when it assigned its disabled umpires to officiate in the one match, a Geelong and District Football League under-18 game between Inverleigh and North Geelong. The field umpires were **Daniel Dorling** (learning disability) and **Nick Kocsi** (cerebral palsy), while the goal umpires were **Luke McLean** (Aspergers syndrome) and **Jake Baker-Brooks** (autism). **Terry Maloney** (acquired brain injury) is on Geelong's regular boundary umpires' panel, but he was joined on this occasion by three draftees with intellectual disabilities who had never acted as football officials. **Ellen Robinson**, **Cassie Berry** and **Sam Sullivan** are said to have enjoyed their debuts as boundary umpires despite lacking power when throwing the ball back into play. The two ruckmen often contested the knock just inside the boundary line, but players from both teams accepted the terms of their game and were happy to play on regardless of the efficacy of the throw-in.

From <http://www.theage.com.au/news/rfnews/teams-left-high-and-dry-as-umpires-strike/2009/07/07/1246732331717.html>

## Kevin Rudd taps into concerns on autism

Andrew Fraser | July 22, 2009

Article from: [The Australian](#)

**A SMALL centre for autistic children on Brisbane's northside may have won a visit from Kevin Rudd in a charity auction, but the Prime Minister showed yesterday that he is highly sensitive to autism in the broader community.**

Mr Rudd yesterday morning met staff and students during a visit to the AEIOU Centre for Children with Autism at Bray Park, which won the prime ministerial visit as a prize at a charity auction.

After the visit, Mr Rudd said figures presented to him at the centre showed that each year there were about 2000 children born in Australia with an autism disorder. He said the government was providing help in two ways, the first of which was that \$190million had been committed in a previous budget to assist families with an autistic member.

He said the second was the construction of half-a-dozen autism-specific early childhood centres around the country.

"One of these is being constructed at Griffith University here in Brisbane, and we're discussing with AEIOU how we can expand those services in the future," he said.

"We haven't reached any conclusions on that but, the truth is 2000 kids a year is a big impact on families. The gap is large. How do we intelligently close it?"

"That's why we're talking to experts in the field."

The Prime Minister has a personal but low-key connection with autism, as his wife Therese Rein revealed at a Brisbane lunch earlier this year that her brother had suffered from autism but had been helped a great deal by the sensitivity of her parents to his condition.

She said that his behaviour as a two-year-old was "terrifying for a parent", but because he had been sensitively handled he is now married with children and has a full-time job.

Brisbane's Courier-Mail newspaper ran a report on Ms Rein's speech but was contacted by the Prime Minister's office, who asked it to drop the story and offered an exclusive interview with the Prime Minister's wife, but the story had already been published in the newspaper's country edition.

From <http://www.theaustralian.news.com.au/story/0,25197,25817908-5006786,00.html>

## Researchers See Recovery From Autism

***Study Shows Some Children May 'Move off' the Autism Spectrum***

By [Kathleen Doheny](#)  
WebMD Health News

Reviewed by [Louise Chang, MD](#)

May 11, 2009 -- One in 10 children diagnosed with [autism](#) or [autism spectrum disorders](#) may recover, says a researcher who presented data at the recent International Society for Autism Research meeting in Chicago.

"We don't know for certain what percent of children are capable of moving off the spectrum," Deborah Fein, PhD, the study's lead author and a Board of Trustees Distinguished Professor of Psychology at the University of Connecticut, Storrs, tells WebMD. "It's probably in the neighborhood of 10% or 20%."

In her research, children who received a treatment known as applied behavioral analysis and got it early seemed to be more likely to recover.

Fein draws the one in 10 figure from her previous research and from the reported results from her ongoing study, in which she and colleagues evaluated children ages 9 to 18 "who clearly had a diagnosis of autism or autism spectrum disorder and have moved off the spectrum."

The researchers' report at the meeting looked at the results of three groups:

- 20 "optimal outcome" children (a phrase Fein prefers to "recovered")
- children with "high functioning" autism
- 23 comparison children developing typically

"We are very carefully verifying the early diagnosis and documenting in more detail than has been done before how the kids are turning out," says Fein. While previous reports have also found that some children do move off the autism spectrum, she says most of those have been by researchers involved in a specific treatment. "That doesn't mean [the reports] are not accurate," she says.

In the research, Fein and her colleagues looked back at such measures as head circumference growth patterns, which have previously been suggested to play a role in the development of autism. They found that the rate of head growth followed by deceleration was greater in the optimal outcome and high-functioning autism groups than in the comparison group. But the head-growth patterns were not different in the optimal outcome and high-functioning groups.

They found that above average IQ may help the recovered group normalize and speculated that the above average IQ may help the recovered children to compensate.

Most of the children who recovered received early applied behavioral analysis treatment, an intensive program that aims to improve problem behaviors, Fein found. They got it at a young age, she says, typically before age 4 or 5.

But she adds this caveat: "What I really want to get across to parents here is, if a child does not have this recovery, it doesn't mean the child didn't get good care. There are clearly a minority of kids with autism who have the potential to reach this outcome."

It's long been known that children with autism tend to also have coexisting conditions such as attention problems and [anxiety](#), and Fein also found that even in the "recovered" children, the other conditions persist.

Nearly three-quarters of the optimal outcome children still had problems such as attention deficit hyperactivity disorder, [depression](#), or [phobias](#). Currently, eight of the children still suffer from the problems, she reports.

### ***Two Families' Stories***

Leo Lytel was diagnosed with classic autism at age 2, recalls his mother, Jayne, who enrolled her son in Fein's study.

By the next year, the diagnosis was moved from a diagnosis of autism to PDD-NOS (pervasive developmental disorder -- not otherwise specified). "He was still on the spectrum," she tells WebMD. Leo got intensive early intervention, including behavior modification, language treatments, and speech and occupational therapy, Lytel says.

"He made remarkable progress from the very beginning," says Lytel. Leo, now 9, is one of the "optimal outcome" children in Fein's study. "He no longer meets the diagnosis for a child on the autism spectrum," his mother says. She credits the early intervention.

Karen Siff Exkorn's son Jake was also diagnosed with autism at age 2, she says. "We hired a team of therapists who literally came to our house every two hours," she tells WebMD. "My husband and I did it over the weekend. We did that for two full years," she says.

At age 4, Exkorn took Jake back to the developmental pediatrician. "She ran him through a battery of tests and gave me the pronouncement: 'Your son is recovered.'"

That was eight years ago. Jake, too, was one of the optimal outcome subjects in Fein's study. Today, Jake is 12, goes to [sleep](#)-away sports camp and is considered a leader by his teachers, Exkorn says.

### ***Autism Recovery: Perspective***

In response to the research findings, Geraldine Dawson, PhD, chief science officer for Autism Speaks and a research professor of psychiatry at the University of North Carolina Chapel Hill, says, "We are more hopeful than ever about the long-term outcome of children with autism. We now know that some children can actually recover from autism."

Like Fein, she cautions that the children, once recovered, are at higher risk for anxiety, attention problems, and other difficulties.

Just as Fein also suspects, Dawson says that behavioral interventions likely played a role for the optimal outcome children.

For parents whose children don't move off the spectrum, Dawson says: "It's important to remember that although all kids don't recover from autism, the majority of kids do get better when intervention is provided."

The findings about recovery, reported by many others, are credible, says another expert, Sally J. Rogers, PhD, senior scientist at the MIND Institute and professor of psychiatry and behavioral sciences at the University of California, Davis. She says the crucial study finding is that "optimal outcome children continue to have neurodevelopmental and behavioral difficulties. Even when classic [symptoms of autism](#) are reduced, other problems often persist."

For consumers, the message is not to categorize the disorders. "These disorders -- autism, [ADHD](#), autism spectrum disorders" aren't entirely separate, Rogers says, but rather on a spectrum.

An estimate of a 10% recovery rate for those with autism seems plausible, says Martha Herbert, MD, PhD, a pediatric neurologist at Massachusetts General Hospital and Harvard Medical School, Boston. In the past, estimates of recovery have ranged from 3% to 25%. Among autism experts, she says, there is a growing consensus that recovery is possible.

"More and more people are beginning to think autism is not entirely 'hard-wired,'" Herbert tells WebMD. Herbert was a co-author on one of Fein's previously published papers, but is not a co-author on the research presented in Chicago. She serves also as director of the treatment-guided research initiative with the Autism Society of America.

From <http://www.webmd.com/brain/autism/news/20090511/researchers-see-recovery-from-autism>

*More links ...*

[http://www.telegraph.co.uk/health/children\\_shealth/5298367/One-in-10-children-with-autism-overcome-condition-by-age-nine-study-finds.html](http://www.telegraph.co.uk/health/children_shealth/5298367/One-in-10-children-with-autism-overcome-condition-by-age-nine-study-finds.html)

[http://www.usatoday.com/news/health/2009-05-08-autism-recover\\_N.htm](http://www.usatoday.com/news/health/2009-05-08-autism-recover_N.htm)

[http://blog.syracuse.com/healthfitness/2009/05/autism\\_recovery\\_research\\_sugge.html](http://blog.syracuse.com/healthfitness/2009/05/autism_recovery_research_sugge.html)

<http://news.medill.northwestern.edu/chicago/news.aspx?id=132909>

<http://www.startribune.com/lifestyle/health/44623022.html>

<http://www.healthnews.com/family-health/child-health/can-children-recover-autism-3108.html>

<http://www.medicinenet.com/script/main/art.asp?articlekey=100210>

<http://www.cbc.ca/health/story/2009/05/11/autism-children-recover.html>

<http://abcnews.go.com/Health/wireStory?id=7540481>

[http://www.msnbc.msn.com/id/30645770/ns/health-mental\\_health/](http://www.msnbc.msn.com/id/30645770/ns/health-mental_health/)

## **American Psychiatric Association (APA)**

*Following are a few items from the APA website relating to PDD and the coming DSM-V ...*

### **Current Status and Activities of the DSM-V Task Force, Study Groups, and Work Groups**

The sixth meeting of the DSM-V Task Force was held October 26-27, 2008. The four DSM-V Task Force Study Groups on cross-cutting issues (Lifespan Developmental Issues, Diagnostic Spectra, Gender and Cross-Cultural Expression, and Psychiatric/General Medical Interface) have met face to face in their respective groups and brought their recommendations back to the full task force for discussion during each of the task force meetings. Each study group has held approximately 15 conference calls since their formation, in April 2007. A fifth study group, charged with working to implement measures of impairment across diagnoses, has been formed, and held its first in-person meeting October 7-8, 2008.

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### **Neurodevelopmental Disorders Work Group**

*Susan Swedo, M.D.*

The Neurodevelopmental Disorders (ND) work group's discussions have focused on three areas:

1. Possible modification of ADHD criteria to allow for co-morbidity of autism and ADHD (currently excluded). The ADHD & Disruptive Behavior Disorders Work Group has agreed to consider this possibility.
2. Discussion of the validity of Rett's disorder as a separate disorder and inclusion of a new modifier within the Autism Spectrum Disorders (ASD), which might include genetic and medical disorders and other biologically-definable conditions.
3. How to address Pervasive Developmental Disorders – Not Otherwise Specified (PDD-NOS). The individuals currently diagnosed with PDD-NOS may still be described in DSM-V, but the work group will discuss whether they can redefine ASD in such a way that the PDD-NOS diagnosis isn't necessary, as this diagnosis currently captures a very heterogeneous group of individuals.

The ND Work Group will be seeking additional feedback from advisors and other experts prior to "finalizing" any recommendations.

Questions still under active discussion for ASD include:

1. How to describe the "spectrum" of disorders now known as ASD (e.g., how many domains will define the disorder);

2. What is the specificity of repetitive behaviors in ASD and how might they be better defined;
3. Whether Childhood Disintegrative Disorder (CDD) is a unique and separate disorder, and if so, what are its defining characteristics;
4. Whether autism is a life-long diagnosis or whether it is possible to recover/remitted to the point where the diagnosis is no longer applicable;
5. Whether Asperger's disorder is the same as "high-functioning autism";
6. How the DSM-V can alert clinicians to common medical comorbidities (including genetic disorders, epilepsy/EEG abnormalities and sleep, or GI problems) and potential biomarkers;
7. How to include consideration of severity and impairment in diagnosis (currently defined as "qualitative impairments") and how to integrate these with the overall structure of DSM-V; and
8. How/where to discuss cultural influences on diagnosis (e.g., Korean use of reactive attachment disorder rather than ASD to avoid family stigmatization).

The following issues are being evaluated by subcommittees of the ND work group: core criteria and domains; CDD and regression; genetics and biomarkers; Asperger's disorder; and the Gender, Lifespan and Cultural Study Groups. Secondary data analyses are underway to address each of these areas.

The Neurodevelopmental Work Group is also charged with examining definitions of intellectual disabilities and learning disabilities. Two subcommittees are addressing these issues – Intellectual Disabilities (ID) and Learning Disabilities (LD). Advisors have been chosen for these subcommittees and new definitions of the LDs and IDs are being examined by a multi-disciplinary, internationally representative committee.

From <http://www.psych.org/MainMenu/Research/DSMIV/DSMV/DSMRevisionActivities/DSMVTaskForceReport.aspx>

## ***Report of the DSM-V Neurodevelopmental Disorders Work Group***

**Susan Swedo, M.D., April 2009**

The Neurodevelopmental Disorders Workgroup met in Arlington VA on April 21-22 and discussed the following recommendations for potential changes to DSM-V diagnostic criteria. No final decisions have been made about the changes and feedback will be sought from professional and lay communities before the Workgroup finalizes their recommendations.

### ***PERVASIVE DEVELOPMENTAL DISORDERS (PDD)***

1) The Workgroup is considering a change in DSM-V that would replace the Pervasive Developmental Disorder (PDD) category with the title "Autism Spectrum Disorders" (ASD). The change would utilize a single diagnosis for the disorders currently entitled: Autism, PDD-NOS and Asperger disorder. Several factors support making this change:

A single spectrum better reflects the pathology and symptoms.

Separation of ASD from typical development is reliable and valid, while separation of disorders within the spectrum is variable and inconsistent.

Individuals with autism, PDD-NOS or Asperger disorder often are diagnosed by severity, rather than unique, separate criteria defining the three diagnoses.

2) To better reflect the symptomatology and clinical presentation of ASD, changing the three current symptom domains (social deficits, communication deficits and fixated interests/repetitive behaviors) to two (social communication deficits and fixated interests and repetitive behaviors) is also being considered.

Streamlining the current PDD (ASD) criteria to better clarify diagnostic requirements is being examined. The criteria might be presented as relatively brief “bullets” with more extensive examples provided in the accompanying text to better describe symptom presentations at various ages, developmental stages and levels of cognitive functioning. Gender and cultural factors will also be considered to ensure that the ASD diagnosis is made appropriately in diverse patient populations.

3) Symptom severity for ASD could be defined along a continuum that includes normal traits, subclinical symptoms and three different severity levels for the disorder. One possible model:

	Social Communication	Fixated Interests and Repetitive Behaviors
Most severe ASD	Minimal or no social communication	Nearly constant, complete preoccupation, strongly resists interference with ritual
Moderately severe ASD	Some social communication but interactions noticeably disturbed	Frequent and interfering rituals, repetitive behaviors and fixated interests
Less severe ASD	Clear impairments in social communication. Meets all diagnostic criteria including symptom severity greater than threshold	Occasional rituals, repetitive behaviors and fixated interests; some interference
Subclinical AS Symptoms	Has some symptoms from one or both domains but no significant interference or impairment.	Odd mannerisms, some excessive preoccupations but distractible, may have ritualized behaviors but they don't interfere with daily activities
Normal Variation	Socially isolated or “awkward”	Some ritualized behaviors and preoccupations but these are normal for developmental stage and cause no interference

### ***INTELLECTUAL DISABILITIES***

DSM-IV uses the term, “Mental retardation” (MR) to describe cognitive deficits. This term is outdated and considered pejorative by many, so the work group is considering a change to the term “Intellectual Disabilities”.

The usefulness of the four current categories (Mild MR, Moderate MR, Severe MR and Profound MR) is being examined, in comparison with a single category of Intellectual Disabilities, with diagnostic specifiers for 1) IQ and 2) Adaptive functioning.

The Workgroup will seek feedback (through RFIs and meetings with stakeholder groups) on these changes in definition, as well as on the specific criteria to be proposed for the intellectual disabilities in DSM-V.

From <http://www.psych.org/MainMenu/Research/DSMIV/DSMV/DSMRevisionActivities/DSM-V-Work-Group-Reports/Neurodevelopmental-Disorders-Work-Group-Report.aspx>

### ***Autism and Other Pervasive Developmental Disorders Conference (February 3-5, 2008)***

See <http://www.psych.org/MainMenu/Research/DSMIV/DSMV/DSMRevisionActivities/ConferenceSummaries/AutismConference.aspx>

### ***Obsessive Compulsive Spectrum Disorders Conference (June 20-22, 2006)***

<http://www.psych.org/MainMenu/Research/DSMIV/DSMV/DSMRevisionActivities/ConferenceSummaries/ObsessiveCompulsiveSpectrumDisordersConference.aspx>

### ***Treatment of Psychiatric Disorders***

<http://www.psych.org/MainMenu/EducationCareerDevelopment/LifeLongLearning/AnnualMeetingOnline/TreatmentofPsychiatricDisorders.aspx>

The third speaker addressed "Autistic learning disabilities and autistic learning styles: a framework for developing individualized treatment plans for autistic spectrum disorders," and categorized a number of the problems that people with autism have and demonstrated how to tailor treatment approaches to the problems. We don't have good treatments yet for these conditions. Motivation and intellectual ability are important in determining the outcome of treatment. She stressed that people with ASDs can have a verbal age at one level and a performance age at a much older level. He may do well with computers but can't deal with the social aspects of the workplace. You must help families learn that at some point the person's life is his own and not the parents. Finding ways to motivate the patient is extremely important. It helps motivate the patient if you understand routines, interests, and their capacity for social appraisal.

### ***Other links relating to DSM-V development***

- <http://www.psychiatrictimes.com:80/display/article/10168/1425378>
- <http://www.psychiatrictimes.com/display/article/10168/1425383>
- <http://www.psychiatrictimes.com/display/article/10168/1420772>

## **Clarification of the definition of PDD-NOS**

Autism was first included in *Diagnostic and Statistical Manual of Mental Disorders, Third Edition (DSM-III)* in 1980 in a new class of conditions--the Pervasive Developmental Disorders (PDD). A residual category, Atypical PDD, was also included and encompassed difficulties characterized by problems in social interaction and problems in communication or restricted/unusual interests similar to those observed in autism but which did not meet full criteria for either infantile autism or childhood onset pervasive developmental disorder. By implication, individuals with Atypical PDD had to exhibit some problem in the social area **and** either in communication or unusual interests. In *Diagnostic and Statistical Manual of Mental Disorders, Third Edition, Revised (DSM-III-R)* the name for the subthreshold class was changed to Pervasive Developmental Disorder Not Otherwise Specified (PDDNOS) but otherwise the approach to diagnosis was the same.

Major changes were made the PDD category in the *Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition (DSM-IV)* based, in part, on a large, multi-site, international field trial. However, an editorial change was made in the description of PDDNOS during the final phase of production that had an unintended effect on the definition of PDDNOS. Instead of requiring "impairment in social interaction and in verbal or nonverbal communication skills" (*DSM-III-R*, p. 39), *DSM-IV* states that the "category should be used where there is a severe and pervasive impairment of reciprocal social interaction or verbal and nonverbal communication skills, or when stereotyped

behavior, interests, and activities are present” (*DSM-IV*, pp. 77-78). Thus, a child with an impairment in only one area (e.g., a child with stereotyped behavior, interests and activities but without evidence of disturbed social interactions could theoretically qualify for a diagnosis of PDDNOS.

To assess the impact of the *DSM-IV* wording, Volkmar and colleagues performed a series of reanalyses of the *DSM-IV* autism/PDD field trial data (Volkmar FR, Shaffer D, First M. PDD-NOS in *DSM-IV*. *J Autism Dev Disord* 2000 Feb;30(1):74-75). A series of comparisons were conducted to evaluate sensitivity/specificity. Using clinicians' judgment of the presence or absence of PDDNOS as the standard, the *DSM-IV* wording had an excellent sensitivity of .98. However, the specificity was only .26, i.e., about 75% of cases identified by the clinician as not having PDDNOS (true negatives), were incorrectly identified as having PDDNOS according to the *DSM-IV*. These results lend support to the concern that the *DSM-IV* wording inappropriately broadened the PDDNOS construct. If problems are required in the social area and either communication or restricted interest (i.e., at least 2 criteria present one of which must be from the social area) the sensitivity was .89 and specificity .56.

These results supported a change in the wording of PDDNOS to revert to the original construct. The new wording in the *Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition, Text Revision (DSM-IV-TR)* is as follows:

“This category should be used when there is a severe and pervasive impairment in the development of reciprocal social interaction associated with impairment in either verbal and nonverbal communication skills, or with the presence of stereotyped behavior, interests, and activities, but the criteria are not met for a specific Pervasive Developmental Disorder, Schizophrenia, Schizotypal Personality Disorder, or Avoidant Personality Disorder.”

From <http://www.psych.org/MainMenu/Research/DSMIV/DSMIVTR/DSMIVvsDSMIVTR/SummaryofPracticeRelevantChangestotheDSMIVTR/PDDNOS.aspx>

## **The curious incident of the straight-A student**

Alex Goodenough was the cleverest kid in his school - so why didn't he get a sixth form place? Decca Aitkenhead talks to his family about the impact of Asperger's

Alex Goodenough talks about his autistic spectrum disorder, Asperger's.

When Alex Goodenough was 13, his English teacher asked his class to write the first chapter of a novel. Alex began writing his, and after chapter one he thought he might as well carry on. He kept writing and writing - about space-faring aliens killing each other - and when the day came to submit his work, he handed in 97,000 words. An entire novel.

"I noticed it was bigger than anyone else's," he says today. He thought the teacher would like it. "I judge books by how many aliens get shot - and everyone died in the end." Instead, he got "a thinly veiled comment about how important it is to wrap things up nicely - to write only what you can write in the duration of a Sats exam."

...

More? See <http://www.guardian.co.uk/lifeandstyle/2009/jul/04/autism-asperger-education-society>

## **A savvy savant finds his voice**

Peter Wilson, Europe correspondent | *January 31, 2009*

**DANIEL Tammet turns 30 today and is quite pleased because he likes that number. Not the age, the number. "Thirty is round but also kind of curvy and shiny and green because three is green so that gives it its colour," he explains in a calm, gentle monotone.**

Tammet's mind probably works differently from yours and mine: to him each number has its own shape, colour and even mood.

"I like 30 because it is smack bang in the middle between prime numbers 29 and 31. Prime numbers are fairly rare anyway and numbers that are separated by two are even rarer."

...

More? See <http://www.theaustralian.news.com.au/story/0,,24986084-26040,00.html>

## **Letters**

Dear Editor,

We are writing to invite your organisation to participate in a study entitled, 'Adjusting to being a Sibling of an Individual with Autism or Psychosis'. The research is being conducted by Master of Psychology student Angeline Ho, and is supervised by Associate Professor Sabine Hammond from the School of Psychology. The study has been approved by the Human Research Ethics Committee of the Australian Catholic University.

We would like to request your organisation's co-operation in assisting us to recruit participants for this research project. The organisation's participation will involve posting the short summary in A4 updates. Adults (18 years and above) affiliated with your organization, who have a sibling with autism or psychosis will be invited to participate in this project.

Please find attached an application form which includes a short summary of the project.

If you have any questions, please do not hesitate to contact me, [angelinehtt@gmail.com](mailto:angelinehtt@gmail.com).

Thank you for considering my application.

Kind regards,  
Angeline Ho

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Hi Bob,

I found this video to be a good overview of the scientific backing of DAN protocols (cellular level chemical pathways disrupted by vaccines).

<http://www.vimeo.com/2504978>

It is 30 minutes with 15 minutes of questions.

Kerrie

Hello again

Asperger Services Australia is proud to be able to present the World Inaugural Seminar about "Girls and Women with an Autism Spectrum Disorder" on Friday 7th August and Saturday 8th August. Venue The Holiday Inn, Roma Street, Brisbane (Transit Centre).

Keynote Speakers Prof Tony Attwood (world renowned Clinical Psychologist) and Dr Michelle Garnett (Clinical Psychologist, proprietor of Minds & Hearts Clinic) and various guest speakers.

For more information please click on the link below or ring the office on 07 3865 2911.

[http://www.asperger.asn.au/News/Archive/09-06-24/Girls\\_and\\_Women\\_with\\_an\\_Autism\\_Spectrum\\_Disorder.aspx](http://www.asperger.asn.au/News/Archive/09-06-24/Girls_and_Women_with_an_Autism_Spectrum_Disorder.aspx)

Kind regards  
Stefanie

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### ***Information About The Luke Priddis Foundation***

To whom it may concern,

We note that you have placed a copy of a recent Sunday Telegraph newspaper article, about the Luke Priddis Foundation, on your website, refer attached link

<http://a4.org.au/a4/node/103>

We thought that your members and those who visit your site, might like to know that the Office of Liquor, Gaming and Racing (OLGR) review of the Luke Priddis Foundation has now been finalised. The review found that "funds have been accumulated and applied in accordance with the Charitable Fundraising Act and the Foundation's charitable objectives" and that whilst some procedural breaches relating to record keeping were identified, "Inspectors concluded that these breaches were unintentional and consistent with a lack of experience and knowledge of requirements by volunteers".

Further details and copies of Press Release both from the OLGR and Luke Priddis Foundation, are available on our website [www.lukepriddisfoundation.com](http://www.lukepriddisfoundation.com)

#### **Shonagh Bennett**

Administration and Community Liaison Officer

Luke Priddis Foundation

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## 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.

*Anti-spam: change -at- to @ in email addresses.*

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

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