

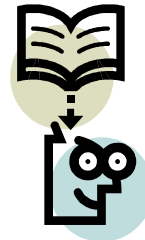
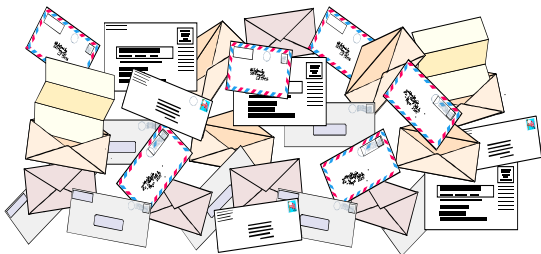
## Newsletter

MARCH / APRIL / MAY / JUNE 2010

ISSUE 87

Welcome to the first Newsletter for 2010. Apologies for it's lateness. Two of our committee members have left us, and it has been very difficult for the remaining committee members to manage PsychDD. We're doing the best we can, and *we would warmly welcome any interest from members in joining the committee*. There is more information about this later in the newsletter. This newsletter is an extra-big issue, with information about several upcoming events (not just PsychDD events), as well as various pieces of other information. Please be mindful if printing, and just print the parts you want.

Andrew Marynissen, Newsletter Editor



## Call for Contributions

Dear Readers, while the main purpose of this newsletter is to publicise PsychDD events, some of you have indicated that you would like to see more. I would also like to make this newsletter better, but I need help from you, the members.

Contributions are requested from members, and are needed to make this newsletter the powerhouse of information it has the potential to be. Contributions can be anonymous. It could be as simple as a link to a website. Comments on talks, forums, books, tests and tools, conferences, courses and symposia are most welcome.

I do my best (with the time I have) to try and find interesting information, but as you can see I would benefit from member contributions, no matter how small.

If you have anything to contribute, please email me at [andrewm6@chw.edu.au](mailto:andrewm6@chw.edu.au)

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# From the Chair

Dear Members,

Welcome to the first Newsletter in 2010. As in previous years, the Committee has resumed their work for the calendar year in February.

## Committee Nominations for 2010

Unfortunately the New Year started with some bad news, as two of our valuable members have resigned from their involvement in PSYCHDD committee, due to work or family commitments. I would like to take this opportunity to thank Gabriela Bilibio (our Workshop Coordinator) and Berindah Aicken (the Award Coordinator) for their dedication and fantastic contribution over the past two years and wish them all the best!

This means that we have now two positions vacant and in need to be urgently filled. Anyone who would like to dedicate their time and join our committee, please do not hesitate to contact either myself or John Wagner or Andrew Marynissen (contact details appear later in the newsletter).

## Feedback on 2009 Annual Conference

I hope you all enjoyed the XVIII Annual Conference as well as the pre-conference workshop in "Assessing mental health problems in adults with DD, using Mini PASADD", facilitated by our guest trainer, Dr Steve Moss from UK. As in previous years we would like to thank you for your feedback and your valuable suggestions, which will be taken into consideration when planning for this year's events.

## Other matters

I would like to share with you some personal experience, which has recently made me think about the issue of grief and intellectual disability, which impacts on our clients can be often underestimated or misunderstood.

A week ago, a horrible plane crash took place, which killed the Polish President, his wife and many high profile representatives from political, cultural and religious elites. This event has affected me personally, not only because of my background, but also because one of my friends, who was an MP and a father of a young man with Autism was on that plane. Some of my other friends, who I spoke to, after receiving this horrific news made a comment, which struck me at the time: "It's a blessing that his son does not understand what happened and does not have to go to the funeral." I was surprised that there are still people in the community, who think that a person with a developmental disability does not experience grief and loss and therefore does not have to be included in the collective grieving process the other family members go through.

As a psychologist working in the disability sector, for years I have been advocating for the rights of people with developmental disabilities to experience grief and be able to participate in traditional burial ceremonies. Psychologists working in developmental disability are often in a position to advise and to support an individual and their family to help them make important decisions at that time. The level of participation and involvement of a person with a developmental disability should be determined individually; on a case by case basis, taking under consideration family wishes, level of understanding, emotional resilience and many other factors, to prevent any further trauma.

How well are we prepared for this task here in Australia? What training is available to prepare us for this job, which if not done properly, can seriously traumatise our client for life? ...Just some food for thoughts...I would like to hear from you about your professional experience with clients experiencing grief and loss and good training opportunities you can recommend...

Best wishes and regards

*Ewa Geba*  
*Chairperson, PsychDD*

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## PSYCHDD Conference 2009 Evaluation Feedback

The following information is based on the 26 Conference Evaluation forms that were returned to us. Thank you for your feedback.

### Did the Conference meet your needs and expectations?

Of the 23 responses to this question, 17 people said 'yes', 4 comments suggested 'yes' and 2 comments suggested 'no'.

Comments included appreciation of the range of speakers and topics, interest value, as well as the idea of getting so many psychologists together who work in a specific field (developmental disability).

### Have you any comments about the quality of the presentations in general?

Of the 20 responses to this question, 8 people said that the quality was excellent or very good, 5 said good, and 1 said fine.

Most comments related to specific presenters, ranging from detailed to basic presentations, and from criticism to high praise, with some comments also being related to the presenters' difficulties completing their presentations within the time limits.

### Which presentation did you find most worthwhile and why?

22 people responded to this question

All presentations were mentioned at least once. Presentations getting the greatest number of mentions included (in order of popularity):

1. *Impact of Trauma on Development for Young People with a Disability* – Damon Williams and Jenna Mayhew
2. *Future Directions for Psychology in Disability Services* – David Manchester
3. (a tie between 2 presentations)  
*Challenging Behaviour in Intellectual Disability: An Argument for Integrated services* – Julian Trollor  
*Beyond BIS Plans – Working with intensive Needs Families* – Jessica Radovan

### Suggestions for 2010 Conference themes, topics and speakers

11 people responded to this question. *Themes, topics and speakers have all been grouped together, as it was difficult to distinguish between topics and themes.*

- Working with families with high Expressed Emotions
- Play therapy with children and young people with an intellectual disability
- Something from the Australian Childhood Foundation (good presenters)
- Dr Bruce Chenoweth, child psychiatrist
- Autism in adults
- ADHD in adults
- Neuropsychiatric/ Neurobiological syndromes and behavioural phenotypes
- Psychopharmacology (x2)
- Academic speakers from universities
- Parent/ consumer perspectives of services and issues (x2)
- Sophie Kavanagh and Dr David Dossetor were mentioned specifically regarding dual diagnosis and psychopharmacology
- Carlos Cruz and Tom Tutton were mentioned specifically regarding autism
- Anything with strategies 'How to...'

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- Assessment tools used in disability
  - Grief and loss in people with ID and how to best support them
  - Psychologists and psychiatrists from health

### **Comments about the Venue of the Conference**

Of the 20 people that responded to this question, 8 people said 'excellent', 6 people said 'good', 1 person said 'fine';

Most comments were positive and addressed the parking and location of the venue. As usual it was difficult to please everyone regarding the room temperature, with comments ranging from too cold to too hot.

### **Comments about the catering**

Of the 24 people who responded to this question,

3 people said they thought the catering was excellent or delicious;

6 people said it was very good or great;

8 people said it was good;

4 people said it was OK or fine.

1 person said 'very bad' and was unimpressed with the limited vegetarian options.

### **Comments about the way the Conference was conducted, eg: Publicity, registrations, programming of presenters.**

18 people responded to this question and comments were variable. Most were positive, with several people asking for copies of the Powerpoint presentations.

### **Comments about the cost of the Conference**

Of the 11 people who responded to this question. 7 people said 'very good', 'great', 'very reasonable', 'very affordable', or 'cheap' (*'cheap' is considered high praise – Ed*); and 3 people said 'good' or 'reasonable'.

Comments related in more detail to the good value-for-money.

### **Suggestions for improvements**

The 10 responses to this question are listed below:

- Would have liked to have a 2-day conference and have workshops to practice some of the skills put forward by presenters.
- Increase to 2 days with presentations and small groups experiential workshops, eg: 45 mins-1 hr presentation on motivational interviewing, then a 30-min workshop on asking open-ended questions, etc.
- Handouts of overheads.
- Doing well! Thanks for all the hard work and dedication.
- Consider Associate Membership for non-psychologists working in developmental disability services (2 people said this)
- A workshop component to get us up and thinking and moving and talking (beyond lunch and breaks)
- Thank you for your hard work.
- Having less speakers and longer periods of time, as often there was not enough time for questions.
- More in-depth/ practical presentations which we as psychologists can make use of.

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## Comments on the Newsletter

5 people commented.

- Good updates on current research. Broader range of topics would also be good.
- Great updates on PsychDD activities, recent publications, members.
- Good - great to receive electronically now.
- Great
- Did not receive (*you should have received a newsletter if you are a member of PsychDD: If you are a member, please email me at [andrewm6@chw.edu.au](mailto:andrewm6@chw.edu.au) and I'll sort it out - Ed*)

*Please note: Contributions from members can be sent to me at [andrewm6@chw.edu.au](mailto:andrewm6@chw.edu.au) - Ed.*

## Comments on the forums

4 people commented

*(since there was no option to comment on the workshops and we only had one forum, I assume the comments related to the workshops as well - Ed)*

- Assessments to evaluate programs, or to self-evaluate; Meeting core competencies of ADHC psychs - how ADHC assessed initial and ongoing skills of psychs; More sexuality topics.
- The cost involved in some forums can be prohibitive (*the forums are free to members, so I'm assuming this referred to the workshops - Ed*)
- Pity they're only held in inner metro area. Unable to attend from other regional areas (*Hopefully we have addressed this with the pre-conference workshop, allowing regional psychs to attend the conference and a workshop in one trip - Ed*)
- Offer in other areas as well, eg: Goulburn, South Coast or Canberra.

## Suggested topics and speakers at forums next year

3 people commented as below:

- Different syndromes and behavioural phenotypes
- Narrative therapy
- Working with children who have had trauma histories
- Psychopharmacology
- Mental health assessment and interventions
- Research papers or research topics

## Issues the association should take up in the future

4 people commented as below:

- As a rural clinician I find it difficult to attend PsychDD events (*we're working on this one, but with a skeleton committee most ongoing projects have been temporarily paused - Ed*)
- Monitoring of quality of private practitioners. Often seeing clients wasting their money
- Would like more notice of forums and conference information, more regular updates of website
- More psychologists in DD!



# PsychDD Forum 1

The Association of Psychologists in Developmental Disability Services



Working with children and adults from Culturally and Linguistically Diverse (CALD) backgrounds in Developmental Disability services

## Brief outline of the presentation:

1. Research - Complex Communication Needs and Bilingualism
2. Research - Intellectual Disability and Families from CALD Backgrounds
3. Attitudes and Cultural beliefs to health interventions
4. Training for parents & families
5. Case Studies
6. Practical strategies
7. Working with interpreters
8. Question and discussion time as needed

**Presenter:** Eunice Law, Consultant Speech Pathologist with Disability Services Australia, and TESOL Practitioner & Language Instructor

Eunice is tri-lingual Speech Pathologist and a Key Word Sign presenter. As a speech pathologist, Eunice has supported children and adults with complex needs across health, education and disability settings, many also from CALD backgrounds. As a language instructor, Eunice has over 14 years of experience teaching children and adults from Culturally and Linguistically Diverse (CALD) backgrounds, with or without complex needs. Eunice has presented at state and national conferences on topics including articulation & language groups; family-based practice; multilingual & multicultural issues. Eunice has a clinical and research interest in AAC, literacy development, multilingual and multicultural issues.

**Date:** Friday 13<sup>th</sup> August 2010  
**Time:** 10:00am to 12:00pm (registration from 9:30)  
**Venue:** Conference Room, ADHC Level 2, 93 George St Parramatta  
**Cost:** PSYCHDD Members: free Non-members: \$10

This forum is directed at those who provide intervention or service to families where intellectual disability is present. You do not have to be a Psychologist to attend. Please forward this flyer to your colleagues.

Booking is **ESSENTIAL**. There are **LIMITED PLACES** so register **EARLY**

To register please email Ewa Geba at [egeba@dsa.org.au](mailto:egeba@dsa.org.au) using PSYCHDD Forum in the Subject line and mention whether you are a PSYCHDD member or not.



# PsychDD Forum 2

The Association of Psychologists in Developmental Disability Services



## Staff Support and Well Being

### About the presentation:

Staff support for clients who have behaviour of concern is critical for client quality of life. However, working with these clients poses its own stresses, risks and challenges for staff and staff well being. There is a real need and duty of care to prevent stress and burnout and better support staff. This forum will address these issues and is intended to be both practical and interactive. The major focus will be upon equipping psychologists, behaviour support practitioners and managers to support and assist staff to maintain quality care, competence and professionalism in the workplace while enhancing staff well being and satisfaction at work.

### Presenter:

Vivienne C Riches PhD  
Psychologist, Snr Research Fellow, Snr Lecturer  
Centre for Disability Studies & University of Sydney

**Date:** September 24, 2010  
**Time:** 9:30am to 12:00pm (registration from 9:15am)  
**Venue:** Conference Room, ADHC Level 2,  
93 George St, Parramatta  
**Cost:** PSYCHDD Members: free Non-members: \$10

Please forward this flyer to your psychologist colleagues.

Booking is **ESSENTIAL**. There are **LIMITED PLACES** so register **EARLY**

To register please email John Wagner at [john.wagner@dadhc.nsw.gov.au](mailto:john.wagner@dadhc.nsw.gov.au) using PSYCHDD Forum in the Subject line and mention whether you are a PSYCHDD member or not.



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### Rise in Membership Fees

Dear Members,

When PSYCHDD began in 1990 (as 'Psychddas'), the cost to members for yearly membership was \$10.00. Since the very beginning we have offered a conference every year, as well as 2 forums and a workshop (and more recently 2 workshops and a forum), and 4-5 newsletters a year.

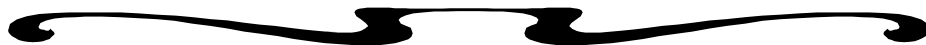
In November 2002 the membership fees rose to \$15.00 a year, which was still good value, and at that time attending a conference or a workshop as a member resulted in a saving of \$10-20, which then covered the cost of membership.

We are a not-for-profit organisation, but we do need to cover the costs of the events we run. In line with the rising costs of venues and catering, we need to increase the fees for operating the Association. We are doing our best to keep the costs down, but membership fees, conference attendance fees and workshop attendance fees will rise slightly in 2010.

In November 2010 the membership fees will rise to \$20.00 a year. This is still good value, and the cost would be made up by attending one of our workshops or conference as a member, which will result in at least a \$20.00 reduction, effectively making membership free if you attend one of our big events (workshop or conference). So when memberships are renewed at the conference this year, you will be asked to pay \$20.00 instead of \$15.00.

Forums will remain free to members, and any of you would be hard-pressed to find a full-day conference (that is catered) for the cost of around \$100.

Andrew Marynissen, Editor



### PSYCHDD 19<sup>TH</sup> ANNUAL CONFERENCE.

Our Annual conference this year will be held on November 26 at the Mercure Hotel, Parramatta. Please put the date in your diary so you can be sure to be available to attend. A registration form will appear in the next Newsletter and you are strongly encouraged to register early.

Please note, under **NO CIRCUMSTANCES** will payments be taken on the day of the conference or afterwards. If your employer will be paying for you to attend, you will have to make arrangements with them in sufficient time for them to process your application and for it to be received by PSYCHDD prior to the close of registrations for the conference. Your registration will only be confirmed once payment is received.



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ASPIA invites you to a one-day workshop on

## **GIRLS AND WOMEN WITH ASPERGER'S SYNDROME**

Presented by

**Professor Tony Attwood**

With contributions from two women with Asperger's Syndrome

**Camilla Connolly and Megan Hammond**

### **About the Workshop**

The presentation describes how girls and women accommodate and camouflage the characteristics of Asperger's Syndrome with examples of the life experiences of girls and women with Asperger's Syndrome. Strategies are provided to help girls and women with Asperger's Syndrome develop friendships and relationships, cope with bullying and teasing, manage emotions and develop a successful career.

### **About the Presenters**

**Professor Tony Attwood.** Tony is a clinical psychologist who has specialised in autism spectrum disorders since he qualified as a clinical psychologist in England in 1975. He works in private practice in Brisbane, but is also adjunct professor at Griffith University, Queensland. His book *Asperger's Syndrome – A Guide for Parents and Professionals* has sold over 300,000 copies and has been translated into twenty languages. He has worked with over 3,000 individuals of all ages with Asperger's syndrome. Tony presents workshops and runs training courses for parents, professionals and individuals with Asperger's syndrome all over the world and is a prolific author of scientific papers and books on the subject. His new book *The Complete Guide to Asperger's Syndrome* was published in October 2006.

**Camilla Connolly.** Camilla Connolly is an artist, writer, public speaker and mother who is formally diagnosed with Asperger Syndrome. She has been selected for major painting competitions in Australia and her work is held in both private and public collections nationally. She runs a blog (<http://thegameofbreathing.blogspot.com>) where she considers everything from living with Asperger's to poetry and fiction writing through to Dante and Roberto Bolano and Glenn Gould. Her life has been rich, complex, eccentric, unorthodox, difficult and even tragic at times, and since diagnosis – comparatively peaceful and joyful. Connolly is also helping to set up support groups and mentoring relationships for Asperger girls and women in Queensland and Northern NSW, where she resides, and believes Asperger People can become empowered to help themselves and be a part of the world around them, in meaningful ways.

**Megan Hammond.** Megan's book "My life with Aspergers" has just recently been published in Sydney by New Holland Publishers. Megan was born in 1972 and it wasn't until she was 26 years old that she was diagnosed with Asperger's Syndrome. Megan was a relatively normal child in her development, but it wasn't until she went to school that it became apparent that all was not well, and so began the search to find a diagnosis. Since her diagnosis Megan has been learning new and different ways of coping with her disability. She's fallen down, picked herself up, and is now on a learning journey that will take her through the rest of her life. During this workshop Megan will introduce herself & her book, share some highlights of her journey and be available for book signings.



## Workshop Details – Girls and Women with Asperger's Syndrome

|                     |   |
|---------------------|---|
| <b><u>DATE</u></b>  | <b>SATURDAY 2 October 2010</b>  |
| <b><u>TIME</u></b>  | 8.30am – 4.30pm   |
| <b><u>COST</u></b>  | \$155 per person (including GST)<br><br>Family Rate - \$135 per person for <u>2 or more</u> registering from the <u>same family group</u>   |
|                     | <b>Price includes all refreshments and lunch</b>  |
| <b><u>VENUE</u></b> | <b><u>The Fitzroy Room</u></b><br><b><u>Campbelltown Catholic Club</u></b><br><b><u>20 – 22 Camden Road, Campbelltown NSW 2560</u></b>  |
|                     | <u>Parking</u> conveniently located on site (including underground)<br><u>Easy walk</u> from Campbelltown Railway Station<br>(Campbelltown or Macarthur Rail Service (airport line or south line))<br><u>Accommodation</u> is available at Rydges on site<br>Campbelltown has been chosen as the location for this event due to its convenient access, not only from Sydney on the M5 Motorway and Cityrail, but also from the South, ie, Southern Highlands, Illawarra & Shoalhaven using Hume Hwy or Appin Road and the West and North of Sydney using the M7 and M5 Motorways. Exit the M5 Motorway at the Narellan Road exit, head East towards Campbelltown, turn left at Kellicar Road (Hurley Street), then immediate right into Camden Road. The Catholic Club will be on your right. |

This Workshop is open to anyone with an interest in this topic  
Limited places available. Please book early to avoid disappointment.



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## Registration Form & Tax Invoice

**How to Register** for Workshop on Girls and Women with Asperger's Syndrome

| Provide name/s of those attending | Price (incl GST)<br>(see Page 2) |
|-----------------------------------|----------------------------------|
| 1.                                |                                  |
| 2.                                |                                  |
| 3.                                |                                  |
| 4.                                |                                  |
| <b>TOTAL COST</b>                 |                                  |

Contact telephone number: \_\_\_\_\_

Email address: \_\_\_\_\_

Special Dietary Requirements: \_\_\_\_\_

### **Select Method of Payment**

- Cheque  (make cheques payable to ASPIA INC)
- Direct Deposit 
  - A/C Name: ASPIA INC
  - Bank: COMMONWEALTH BANK OF AUSTRALIA
  - BSB: 062 340 A/C Number: 1018 1011
  - (Please include your name & "Oct" in deposit details)
- Credit Card 
  - Name on Card: \_\_\_\_\_
  - Credit Card Number: \_\_\_\_\_
  - Expiry Date: \_\_\_\_\_
  - Signature: \_\_\_\_\_

### **Send Registration Form to ASPIA Inc**

- By Mail: PO Box 57 Macarthur Square LPO MACARTHUR NSW 2560
- By Email: [info@aspia.org.au](mailto:info@aspia.org.au)
- Or telephone ASPIA on 0432 507 828 to register and make a credit card payment over the phone.



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## A Powerful Identity, a Vanishing Diagnosis - Article from the New York Times

By CLAUDIA WALLIS

Published: November 2, 2009

It is one of the most intriguing labels in psychiatry. Children with Asperger's syndrome, a mild form of autism, are socially awkward and often physically clumsy, but many are verbal prodigies, speaking in complex sentences at early ages, reading newspapers fluently by age 5 or 6 and acquiring expertise in some preferred topic - stegosaurus, clipper ships, Interstate highways - that will astonish adults and bore their playmates to tears.

In recent years, this once obscure diagnosis, given to more than four times as many boys as girls, has become increasingly common.

Much of the growing prevalence of autism, which now affects about 1 percent of American children, according to federal data, can be attributed to Asperger's and other mild forms of the disorder. And Asperger's has exploded into popular culture through books and films depicting it as the realm of brilliant nerds and savantlike geniuses.

But no sooner has Asperger consciousness awakened than the disorder seems headed for psychiatric obsolescence. Though it became an official part of the medical lexicon only in 1994, the experts who are revising psychiatry's diagnostic manual have proposed to eliminate it from the new edition, due out in 2012.

If these experts have their way, Asperger's syndrome and another mild form of autism, pervasive developmental disorder not otherwise specified (P.D.D.-N.O.S. for short), will be folded into a single broad diagnosis, autism spectrum disorder - a category that encompasses autism's entire range, or spectrum, from high-functioning to profoundly disabling.

"Nobody has been able to show consistent differences between what clinicians diagnose as Asperger's syndrome and what they diagnose as mild autistic disorder," said Catherine Lord, director of the Autism and Communication Disorders Centers at the University of Michigan, one of 13 members of a group evaluating autism and other neurodevelopmental disorders for the manual.

"Asperger's means a lot of different things to different people," Dr. Lord said. "It's confusing and not terribly useful."

Taking Asperger's out of the manual, known as D.S.M.-V for the fifth edition of the Diagnostic and Statistical Manual of Mental Disorders, does not mean the term will disappear. "We don't want to say that no one can ever use this word," Dr. Lord said, adding: "It's not an evidence-based term. It may be something people would like to use to describe how they see themselves fitting into the spectrum."

But the change, if approved by the manual's editors and consultants, is likely to be controversial. The Asperger's diagnosis is used by health insurers, researchers, state agencies and schools — not to mention people with the disorder, many of whom proudly call themselves Aspies.

Some experts worry that the loss of the label will inhibit mildly affected people from being assessed for autism. "The general public has either a neutral or fairly positive view of the term Asperger's syndrome," said Tony Attwood, a psychologist based in Australia who wrote "The Complete Guide to Asperger's Syndrome" (Jessica Kingsley Publishers, 2006). But if people are told they should be evaluated for autism, he went on, "they will say: 'No, no, no. I can talk. I have a friend. What a ridiculous suggestion!' So we will miss the opportunity to assess people."

The proposed changes to the autism category are part of a bigger overhaul that will largely replace the old "you have it or you don't" model of mental illness with a more modern view — that psychiatric disorders should be seen as a continuum, with many degrees of severity. The goal is to develop "severity measures within each diagnosis," said Dr. Darrel A. Regier, research director at the American Psychiatric Association and vice chairman of the diagnostic manual's task force.

Another broad change is to better recognize that psychiatric patients often have many health problems affecting mind and body and that clinicians need to evaluate and treat the whole patient.

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Historically, Dr. Regier said, the diagnostic manual was used to sort hospital patients based on what was judged to be their most serious problem. A patient with a primary diagnosis of major depression would not be evaluated for anxiety, for example, even though the two disorders often go hand in hand.

Similarly, a child with the autism label could not also have a diagnosis of attention deficit hyperactivity disorder, because attention problems are considered secondary to the autism. Thus, they might go untreated, or the treatment would not be covered by insurance.

The new edition, by contrast, will list not only the core issues that characterize a given diagnosis but also an array of other health problems that commonly accompany the disorder. For autism, this would most likely include anxiety, attention disorders, gastrointestinal problems, seizures and sensory differences like extreme sensitivity to noise.

Parents and advocates have been clamoring for an approach that addresses the multiple health problems that plague many children with autism. "Our kids will do much better if medical conditions like gut issues or allergies are treated," said Lee Grossman, president of the Autism Society of America, a leading advocacy group.

The new diagnostic approach addresses another source of confusion: the current labels may change over time. "A child can look like they have P.D.D.-N.O.S., then Asperger's, then back to autism," Dr. Lord said. The inconsistent use of these labels has been a problem for researchers recruiting subjects for studies of autism spectrum disorder.

And it can be a problem for people seeking help. In some states, California and Texas, for example, people with traditional autistic disorder qualify for state services, while those with Asperger's and pervasive developmental disorder do not.

A big challenge for the diagnostic manual team working on autism is how to measure severity in a condition that often causes a very uneven profile of abilities and disabilities. Mr. Grossman gives the example of a woman who serves on an advisory panel to his organization. She is nonverbal and depends on an electronic device to communicate, is prone to self-injury and relies on a personal aide. And yet "she's absolutely brilliant, she runs a newsletter, and she's up on all the science," he said, adding, "Where would somebody like that come out on the rating scale?"

Recent books by people with Asperger's give insights into the workings of some oddly beautiful minds. In "Embracing the Wide Sky" (Free Press, 2009), Daniel Tammet, a shy British math and linguistic savant, tells how he was able to learn enough Icelandic in a week to manage a television interview and how he could recite the value of pi to 22,514 decimal places by envisioning the digits "as a rolling numerical panorama" of colors, shapes and textures.

In "Look Me in the Eye" (Crown, 2007), John Elder Robison describes a painfully lonely childhood and an ability to look at a circuit design and imagine how it will transform sound — a talent he used to invent audio effects and exploding guitars for the rock band Kiss.

Not all people with Asperger's have such extraordinary abilities, and some who do are so crippled by anxiety and social limitations that they cannot hold down a job or live on their own.

Dr. Susan E. Swedo, a senior investigator at the National Institute of Mental Health who heads the diagnostic manual group working on autism, acknowledges the difficulty of describing such a variable disorder. Dr. Swedo said the plan was to define autism by two core elements — impaired social communication and repetitive behaviors or fixated interests — and to score each of those elements for severity.

The trick is to "walk the tightrope of truth," Dr. Swedo said, between providing clear, easily used diagnostic guidance to clinicians and capturing the individual variation that is relevant to treatment. "People say that in autism, everybody is a snowflake," she said. "It's the perfect analogy."

The proposed elimination of autism subtypes comes at the very moment when research suggests that the disorder may have scores of varieties. Investigators have already identified more than a dozen gene patterns associated with autism, but Dr. Lord, of Michigan, said the genetic markers "don't seem to map at all into what people currently call Asperger's or P.D.D."

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Nor have many of these genes been linked to distinct sets of symptoms. Until research can identify reliable biological markers for autism subtypes, Dr. Lord and other experts say, it is better to have no subtypes than the wrong ones.

In interviews, people with Asperger's and mild autism were divided on the prospect of losing the label. Temple Grandin, a Colorado State University animal scientist who is perhaps the best-known autistic American, said Asperger's was too well established to be thrown overboard. "The Asperger community is a big vocal community," Dr. Grandin said, "a reason in itself" to leave the diagnosis in place.

"P.D.D.- N.O.S., I'd throw in the garbage can," she added. "But I'd keep Asperger's."

But some younger people involved in the growing autism self-advocacy movement see things differently.

"My identity is attached to being on the autism spectrum, not some superior Asperger's identity," said Ari Ne'eman, 21, an activist who founded the Autistic Self-Advocacy Network, a 15-chapter organization he has built while in college, adding, "I think the consolidation to one category of autism spectrum diagnosis will lead to better services."

All interested parties will have an opportunity to weigh in on the proposed changes. The American Psychiatric Association is expected to post the working group's final proposal on autism diagnostic criteria on the diagnostic manual's Web site in January and invite comment from the public. Dr. Swedo and company are bracing for an earful.

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## **Autism news from Medical News Today (<http://www.medicalnewstoday.com/sections/autism/>)**

From 'The Guardian' (UK) (article by Sarah Boseley)

### **Andrew Wakefield found 'irresponsible' by GMC over MMR vaccine scare**

Doctor's research triggered a furore and was direct cause of slump in take-up of MMR, which has led to outbreaks of measles in some parts of the country.

Andrew Wakefield, the doctor who claimed to have discovered a link between measles virus, bowel diseases and autism and thereby sparked widespread fear of the combined MMR jab, conducted unnecessary, invasive tests on children, the General Medical Council found today.

Branding him a dishonest, irresponsible doctor, the GMC disciplinary panel, which has sat and heard evidence for 148 days over two and a half years, finally found a long array of charges against him proven. But there were shouts of protest and dismay from the doctor's supporters.

Wakefield and two other doctors at the Royal Free hospital in London were brought before the GMC over the paper they published in February 1998 in the Lancet medical journal.

On the basis of case studies of just eight children, it suggested that measles virus might be linked to inflammatory bowel disease, which in turn might play a role in autistic spectrum disorder.

The paper conceded that the doctors had not found a definite link, but Wakefield, in a press conference, told the world he believed the measles, mumps and rubella vaccines in the MMR jab should not be given in one combined shot, but in single doses, preferably a year apart. It triggered a furore and was the direct cause of the major slump in take-up of MMR which has led to outbreaks of measles in some parts of the country.

The GMC found that Wakefield had flouted the rules in pursuit of his theory – and profit. At the centre of the case against him is the ethical conduct of the trial which resulted in the Lancet paper. The panel found he had subjected 11 children to invasive tests such as lumbar punctures and colonoscopies that they did not need, without ethical approval.

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But investigations revealed more. In June 1997, before the paper was published, he filed a patent as one of the inventors of a vaccine for the elimination of measles virus and for the treatment of inflammatory bowel disease.

In February 1998, the same month as the Lancet paper, he applied for ethical permission to run a trial of a new potential measles vaccine and set up a company called Immunospecifics Biotechnologies Ltd which would produce and sell it. The father of one of the children he had seen with developmental problems and bowel disease would be the managing director. Wakefield tried out the new vaccine on the child, without mentioning it in the medical notes or telling the child's GP. He was also found to have unethically arranged for his son's friends to have blood samples taken from them during his birthday party – for which he paid them £5 each.

Wakefield hit on his theory after seeing children with bowel disease who also had developmental problems. The crucial third step in the hypothesis was the timing of the MMR vaccine: the first shot is given at around 18 months, which is also when autistic spectrum disorders start to be noticed.

In front of the GMC with him were two doctors who were at the time colleagues in the department of paediatric gastroenterology at the Royal Free, Prof John Walker-Smith and Dr (now Prof) Simon Murch. The GMC decided they shared responsibility for the ethical conduct of the trial, although neither one was said to have acted dishonestly.

The trial that Wakefield proposed troubled the ethics committee of the Royal Free. It is a fundamental principle in paediatrics that no child should be subjected to more than a blood test unless it is necessary for their treatment. But Wakefield proposed a barrage of invasive procedures. Dr Evan Harris, the Liberal Democrat spokesman who complained to the GMC, believes the committee should have sought advice from an independent paediatrician. Instead, it asked a gastroenterologist colleague of Wakefield.

The committee gave its conditional approval. The GMC panel decided that those conditions had been flouted – and that the trial had been unethical.

The GMC looked into the cases of eleven children who were entered into the trial. Many rules had been broken. Wakefield's contract was for "experimental gastroenterology" and he was not allowed to treat children, but he ordered tests and procedures that were not necessary for their health. In the interests of proving Wakefield's theory, children were given lumbar punctures in the spine, colonoscopies and barium meals – all significant procedures. Children were enrolled who did not fit the strict criteria for entry to the trial and they had not come from a GP who was referring them because they needed treatment.

Wakefield, now based in the US, has also been found not to have been open with the Lancet. He did not tell them that £55,000 funding for the study came from the legal aid board. Wakefield was advising Richard Barr, a solicitor who wanted evidence to sue the vaccine manufacturers on behalf of the parents of children with autism. It was a clear conflict of interest and should have been declared.

All three doctors will now come back before the panel in April, where the GMC will decide if they are guilty of serious professional misconduct, which could end in one or more of them being stripped of their licence to practise medicine.

Harris said Wakefield's reputation and that of his campaign was "in tatters and it is sad that it has taken so long for this to be demonstrated.

"That the GMC has found Wakefield guilty of unapproved and unnecessary invasive tests, including spinal taps, on young children, is the most damning indictment possible. The findings of failure to declare financial interest are a secondary consideration."

Dr Shona Hilton, of the Medical Research Council, said the scare had a huge impact on parents, undermining their trust in MMR vaccination. "Thankfully confidence is returning and the uptake of MMR vaccine is increasing," she said. "We need to continue rebuilding trust with parents that MMR vaccination is safe and ensure that those parents caring for children with autism do not blame themselves."

Wakefield, who was not at the hearing but spoke outside the GMC offices minutes after the ruling, said he was "extremely disappointed" by the outcome. He said: "The allegations against me and

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against my colleagues are both unfounded and unjust ... and I invite anyone to examine the contents of these proceedings and come to their own conclusion."

He went on: "It remains for me to thank the parents whose commitment and loyalty has been extraordinary."

Thousands of people, mainly parents of autistic children, have continued to support Wakefield. Panel chairman Dr Surendra Kumar was heckled by parents as he delivered the verdicts in central London this afternoon. One woman shouted: "These doctors have not failed our children. You are outrageous."

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### **Why autism sufferers hate hugs**

From: [news.com.au](http://news.com.au) by Tracey Haslam Source: NewsCore February 13, 2010

Many autism sufferers, especially those with Fragile X Syndrome, do not like to be touched.

Scientists may have discovered why many people with autism do not like to be hugged or touched.

They studied individuals with Fragile X Syndrome, a well-known genetic cause of autism and the most common known cause of inherited learning disabilities, the BBC reported.

They found Fragile X results in delayed development of the sensory cortex, the brain region that responds to touch.

Writing in the science journal Neuron, the scientists said that the findings may help explain why people with the condition are hypersensitive to physical contact.

Fragile X syndrome is caused by a mutant gene in the X chromosome that interferes in the production of a protein called fragile X mental retardation protein.

Under normal circumstances, the protein directs the formation of other proteins that build synapses in the brain.

Boys are usually more severely affected with the condition because as they have only one X chromosome.

By recording electrical signals in the brains of mice, bred to mimic the condition, the scientists found that connections in the sensory cortex in the brain were late to mature.

This lateness may cause further problems with the correct wiring of the brain.

The study also found these changes in the brain's connections occur midway through a baby's development in the womb.

Professor Peter Kind, who led the study at Edinburgh University, said: "We've learned these changes happen much earlier than previously thought, which gives valuable insight into when we should begin therapeutic intervention for people with these conditions."

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### **From the Sydney Morning Herald, April 2010**

#### **Autism iPhone breakthrough: From tantrums to app-y days**

ASHER MOSES, Sydney Morning Herald, April 16, 2010

Few can legitimately boast that an iPhone app changed their life but for 10-year-old Grace Domican, unable to speak due to autism, the touchscreen phone has given her a voice for the first time.

Her mother, Lisa Domican, created a picture-based iPhone application to help her communicate and the tool was so successful she is now trialing it in a school for autistic children in Ireland.

Domican, who was born in Australia and lived here until she moved to Ireland in 2001, is also planning to provide it to schools in Australia and is selling both iPhone and iPad versions on the iTunes App Store.



Aspect, Australia's largest non-profit organisation providing support for people with autism, has expressed interest in trialling the app with its clients, while Domican said she had also been in contact with the Woodbury School in Baulkham Hills.

The Grace app is essentially a digital version of the Picture Exchange Communications System - a book of laminated pictures attached to a board by velcro that allows children with autism to build sentences and communicate.

Children with autism are often unable to use and understand expressive language because the developmental disability means those parts of the brain don't work. Some children with autism go on to develop speech, while others never do.

As the child learns new words via pictures they are added to the PECS book, a system that quickly becomes unwieldy, particularly outside the home setting.

"You have to take the photo, print the photo, laminate the photo, velcro it and repeat this every time they decide they like something new," said Domican, whose older son Liam, 12, also has autism.

With the app, which is being sold for \$45 on the App Store with some of the proceeds going to charity, Grace has access to more than 400 symbols and photos in the palm of her hand. She can add new ones herself by taking pictures with the phone's camera.

Domican is able to share new words and interests instantly with Grace's carers and teachers so they can use them in their interactions with the child.

The iPhone's touchscreen was critical as Grace was used to pointing at the pictures in her PECS book, so it was second nature to open and operate the apps.

"With the phone showing exactly what she has requested, it is now very clear to all of us what she needs and we see a huge reduction in frustration behaviour as a result," Domican said.

"Grace is capable of a two- to three-hour tantrum that leaves your ears ringing, so this is a good thing."

Now the app is being trialled on several of Grace's fellow students at a Saplings school in Ireland, designed specifically for children who cannot be taught in mainstream schools. Members of the public have been donating their second-hand iPhones, which are then cleaned up and donated to autism schools.

Domican even credits the app with improving Grace's verbal communication, saying she can now make many three- to four-word verbal requests, such as "I want to drink" or "I want purple chocolate" (Cadbury).

Anthony Warren, Aspect's director for children, young people and families, said he thought the Grace app was "a great idea" but suspected it would not be a substitute for the formal PECS program. He said he was sure Aspect's schools and speech pathologists would be interested in trialling it.

"It certainly sounds as though it would be very motivating and helpful for clients who have higher support needs and who are motivated by that sort of technology," he said.

Domican said she got the idea for the app after seeing iPhone ads on the sides of buses just before the device launched in Ireland. The telco O2 Telefonica supplied her with an iPhone after meeting Domican at a World Autism Day event.

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Last year, Domican tracked down an iPhone developer, Steve Troughton Smith, who helped her make the app. Since the pictures used by Grace were owned by a company, Domican had to draw sketches of each image she would need for a basic vocabulary and then contracted an artist to make professional, digital versions.

Smith created a prototype of the app in September and "by the end of November we had four additional phones and we were trialing it with three more children in the school".

Domican and her family have lived in Ballarat, Melbourne and Sydney. They regularly fly down to visit family in Ballarat.

Liam was diagnosed in the Royal Brisbane Hospital in 2000 and attended the Autistic Association of Queensland school in Brighton for almost a year. Grace was diagnosed by a paediatrician in Ballarat in September 2001, just before the family moved to Ireland.

Domican said she would like to move back to Australia but said at the moment there were inadequate provisions for autistic kids in state-funded schools.

"A one size fits all special needs education would not suit kids like mine and their potential could be lost," she said.



### **The NSW Council for Intellectual Disability (CID) website**

The website for the NSW Council for Intellectual Disability is located at <http://www.nswcid.org.au/>. The organisation represents the interests of people with an intellectual disability. The CID website has an 'easy English' option for people with an intellectual disability.

The website also offers Health Fact Sheets, which are also in standard English and easy English. Topics include: Me and my doctor, After visiting the doctor, Mental health, Going to the hospital for surgery, Me and my medication, and Finding a new doctor.

Coming soon: A health emergency, and Going to the dentist.



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# CALL FOR PAPERS

19th Annual Conference

*Sharing Good Practices to Gain Good Outcomes*

November 26, 2010

Mercure Hotel  
Parramatta

***Presenters are entitled to free registration for the conference***

I am interested in giving a presentation at the 2010 PSYCHDD Conference. The type of presentation I would like to deliver is:

- 45-minute paper
- 30-minute paper
- poster session
- other (please describe) .....

The working title of my presentation is: .....

This paper deals with: (just in broad outline if an abstract is not available at this time)

Name: .....

Address: ..... Post Code: .....

Phone: ..... Fax: .....

email .....

***Intending presenters will be sent information about the conference when their expression of interest is received.***

Please return by **July23** to

John Wagner  
Statewide Behaviour Intervention Service: [john.wagner@dadhc.nsw.gov.au](mailto:john.wagner@dadhc.nsw.gov.au)

Inquiries:  
Phone: 8876 4000



# PSYCHDD

The Association of Psychologists in Developmental Disability Services

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Welcome to the Association of Psychologists in  
Developmental Disability Services  
(PsychDD)

## Jobs

There are currently 2 casual / part time positions available in the Sydney Metro area for Psychologists with experience in disability.

[Click here for more details](#)

## Incorporation

Last year, members of PsychDD unanimously voted in favour of the proposed incorporation rules. As of the 8th of February, 2008, PsychDD is an incorporated not-for-profit organisation. The Certificate can be found [here](#). Our constitution will shortly be available.

## 2008 Conference

The 2008 PsychDD conference (and pre-conference workshop) is

Have you visited the PsychDD website yet? It is located at [www.psychdd.com.au](http://www.psychdd.com.au)

## PsychDD Committee Meetings

Dear members,

Members of PsychDD have the right (and privilege!) of attending the PsychDD Committee meetings.

For anyone interested in attending these meetings, they take place from 3:30 pm to 5:00 pm on 7 occasions throughout the year.

Our current venue is at the offices of Disability Services Australia (DSA), at Suite 4/400 Chapel Rd, Bankstown.

Dates of meetings for the rest of 2010 are:

*Mondays: June 21, August 16, October 11, November 15 (pre-conference meeting), and December 6.*

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## Current PsychDD Committee

|                                      |                   |           |
|--------------------------------------|-------------------|-----------|
| Chair:                               | Ewa Geba          | 4620 9660 |
| Vice Chair:                          | John Wagner       | 8876 4000 |
| Secretary:                           | Andrew Marynissen | 9891 7202 |
| Treasurer:                           | Laura Le Van      | 4620 9660 |
| Newsletter Editor:                   | Andrew Marynissen | 9891 7202 |
| Membership Secretary:                | Andrew Marynissen | 9891 7202 |
| Forum Coordinator:                   | (vacant)          |           |
| Conference Co-ordinator:             | John Wagner       | 8876 4000 |
| Workshop Co-ordinator:               | (vacant)          |           |
| Pre-Conference Workshop Co-ordinator | (vacant)          |           |
| Awards Co-ordinator:                 | (vacant)          |           |
| Webmaster:                           | Matt Frize        | 9841 9264 |
| Publicity:                           | Andrew Marynissen | 9891 7202 |
| Public Officer (incorporation):      | Andrew Marynissen | 9891 7202 |



### **Please consider joining our committee!!**

*As you can see from the list above, we have several vacancies.*

Are You PsychDD Material? You probably are!

Our committee is only a small one, containing **only 5** people at the moment. The job of the committee is to manage PsychDD, ranging from organising forums, workshops and an annual conference, to publicity, newsletters, incorporation, membership and a website as well.

We are looking for Psychologists who would like to become part of our committee. We meet 7 times a year (roughly every 2 months) for 1½ hours on a Monday afternoon. Our current venue is at the offices of Disability Services Australia (DSA), at Suite 4/400 Chapel Rd, Bankstown.

Meeting dates are located on the previous page. Some of us also have responsibilities at forums, workshops and the annual conference.

*Our committee currently has several vacancies, which are likely to affect the operation of PsychDD until they can be filled.*

Please consider joining our committee. We have changed our meeting times to be during business hours for committee members' convenience. If you are interested, please contact one of the committee members. Our numbers are listed (above) in every newsletter, and Andrew's email address is on the front page.



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## PSYCHDD MEMBERSHIP RENEWAL/APPLICATION FORM

Surname: ..... Given names: .....

Employer: ..... Position: .....

Mailing address: work or home: .....

.....

Phone no: work or home:..... fax: .....

E-mail: .....

Are you registered as a psychologist with the NSW Psychologist Registration Board? yes no

If yes, what is your registration status: full or conditional?

What psychology degree(s) do you hold?.....

Years of service as a psychologist working in the field of developmental disability services:.....

How did you find out about PSYCHDD (if you are a new member)?.....

.....

Do you have an area of special interests or expertise in disability work?.....

.....

Are you agreeable to your name and area of interest appearing in a directory of members' interests which we publish from time to time in the Newsletter *and on the internet*? yes no

Tick the contact details you are happy to have included:

mailing address  phone number  email

Please enclose \$15.00 annual membership payable to PSYCHDD and post to

Andrew Marynissen, PECAT  
Locked Bag 4001  
Westmead NSW 2145

***Please note: Membership is GST exempt and valid until the annual conference (November) of that year.***

Event photos (possibly containing attendees) may be published in newsletters and may also appear on the PsychDD website. Please advise if you have an issue with this. Contact: Andrew Marynissen on 9891 7202 (you can also leave a message) or [andrewm6@chw.edu.au](mailto:andrewm6@chw.edu.au), or make a comment on this form.

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### IDEAS FOR FORUMS

We are interested to know what topics members would like to see presented as forums. Please tick three topics from the following list which has been derived from the member feedback form.

- syndromes and congenital disorders
- ageing and developmental disability
- management of challenging behaviour
- dual diagnosis
- new developments in psychological assessment for people with a disability
- cognitive-behavioural strategies
- working with families
- families from other cultures
- other.....

ABN: 22 404 141 513