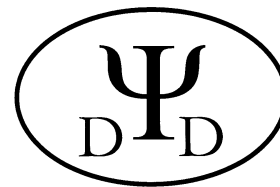

PSYCHDD

THE ASSOCIATION OF PSYCHOLOGISTS
IN DEVELOPMENTAL DISABILITY SERVICES



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Newsletter

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ISSUE 90

Welcome to the mid-year PsychDD Newsletter for 2011. This issue contains information about upcoming events, as well as the write-up from the July forum, as well as the usual bits and pieces. Make sure you get in early to register for our events.

Please be mindful if printing, and just print the parts you want. Enjoy!

Andrew Marynissen, Newsletter Editor

A different message on the front page!

Dear Readers, every single one of you will need to show evidence of *active* Continuing Professional Development. While much will be inactive (attending talks and seminars), there must be a percentage of active training. This usually involves a test at the end, or some other form of evaluation of your learning.

The writing-up of a talk qualifies your learning as *active* because you would have involuntarily learned more-than-normal because you initially took notes, then you typed them up, then had to proof-read them, so effectively you are going over the information several times, which will lead to more learning than if you just took the notes and did no more.

So, if you were to contribute (to this newsletter) a write-up of a talk you went to, you could document it as *active* Continuing Professional Development (in you CPD log) by sheer virtue of having gone through the material several times during the write-up process. This write-up would require a bit more detail than just half a page, and I would suggest at least 1 page if not more, depending on the complexity of the issue.

This way, you could provide some info to the other PsychDD membership through the newsletter, as well as turning your *inactive* CPD into *active* CPD.

Later in this newsletter is a write-up of my ADOS introduction training, which was already active because we had some testing on it, but even if not, my writing up the information has made my learning active because I had to go through the information again several times.

So now there is even more incentive to submit write-ups of talks, tests, articles, etc.

- Andrew Marynissen, Newsletter Editor, andrewm6@chw.edu.au

From the Chair

Dear Members,

Welcome to the 2nd edition to our Newsletter for 2011. The warm weather in the past few weeks has brought some hope that the winter is nearly over....and I am sure that some of you have already started to plan your spring & summer holidays...

News from the Committee

The committee has been very busy in the past few months, so with a great excitement we have welcomed three new committee members: Anita Freeman (from Aspect), Dr Abey Bandaranayaka (private consultant), and Jennifer Povey (Senior psychologist with the House With No Steps). On behalf of all members, I would like to wish the new committee members all the best. We are looking forward to working together on the existing and new projects.

News from the Sector

The move towards the National Disability Insurance Scheme and real person-centred, individualised disability services is well in progress. Following the PCA summit last month, the NSW Government is now looking to get a greater understanding of the needs of people with a disability in the community. This will help to establish a disability service system in NSW that puts decision making control, choice and flexibility for people with a disability at the centre of their support.

As a part of this process, over 100 consultations will be held across NSW and I would like to encourage you to take part in this process. Registrations are open for you to attend the consultation session of your choice.

The consultations commenced on 1st August and will continue until 2nd September 2011 at several locations across the state. The consultation sessions will involve small focus group discussions with people with a disability, their families and service providers so that every participant has an opportunity to have their say. To find out more information or to register, go to www.nswpcaconsult.net or call (02) 4984 2554 or 1300 550 913.

If you can't attend a consultation you can make a submission by emailing pcaconsultations@dhs.nsw.gov.au. If you are interested to find out more about NDIS, go to www.everyaustraliancounts.com.au. On the pages of this website you can find out how the NDIS will help people with disabilities to have better access to services and achieve the best outcomes.

20th Annual PSYCHDD Conference.

The preparations to our 20th (XX) Annual Conference are progressing well. The speaker's slots are almost full. There will be a children's stream and an adult stream as in previous years. As a part of the conference we will also celebrate the 20th anniversary of our association, so please be prepared for loads of fun and some surprises!

Best wishes and regards,

Ewa Geba

Chairperson, PsychDD

Motivational Interviewing in Intellectual Disability

Presented by **David Manchester**, Psychology Practice Leader, Ageing, Disability and Home care (ADHC), along with **Jason Tavares**, Clinical Consultant with the Integrated Services Project and ADHC MI Trainer.

There was a full house (30 people), including several people from the overflow list who were informed at last moment's notice when a few others had to cancel.

There was a fire drill just before the forum, so we all started a bit late.

The following write-up was checked by the presenter himself, with some slight changes made, and permission has been obtained to publish this in the PsychDD Newsletter.

Handouts were provided regarding introduction to Motivational Interviewing (MI), as well as Prochaska & DiClemente's (1983) stages of change model. The stages of change include Pre-contemplation (not aware there is a problem or a need for change), Contemplation (awareness of a problem and possible need for change), Preparation (preparing to make a change), Action (making the change), Maintenance (change has occurred, possibly the end of the cycle, except for...), Relapse (very common in the cycle of change), which may then lead back to Pre-contemplation or Contemplation.

It must be pointed out here that this 2-hour talk was an introduction to a fairly complex area that normally is taught through a 2-day workshop with follow-up and expert feedback.

Motivational interviewing is a therapeutic interviewing style that is based on *listening* to patients. In a typical session, the interviewer does little talking.

A typical (average) person usually finds it very difficult to change their own behaviour (how long did it take to give up smoking? To lose weight? To start spending less money?) What chance does a person with an intellectual disability have? And if an average person wants to change their behaviour, it can sometimes take several years for the change to stick, or even to be started. And yet when a behavioural clinician is called in to help a client change unwanted behaviour, results are usually expected very quickly, so it can be an uphill battle from the start. Given all these difficulties, making change needs to be clever, to minimise the usual difficulties that one encounters when trying to change.

Who is MI for, in the field of developmental disability? The nature of the technique requires the person to have some capability to change their own behaviour. They need awareness of their issues and what is stopping them from changing, as well as why they want to change. Executive functioning (frontal lobe higher-order thinking such as insight and self-awareness) in the patient is required for this technique to be effective. People with an intellectual disability usually have poor executive functioning, which is why they would have a very poor chance of changing their behaviour on their own. This is also the case in people with Traumatic Brain Injury or severe mental illness. The deficits in executive functioning in these populations is similar, and all these populations need the support of others such as family, residential care staff or therapists.

So, Who is MI for in the field of intellectual disability? Usually staff members who work with the client (such as group home staff) or family members trying to implement change at home. A person with a Mild intellectual disability may also be able to benefit from MI directly.

Research has shown that if a person is considering making a change, they will tend to automatically come up with counter-arguments (and hence *resistance*) when given unsolicited advice or suggestions regarding that change. It has been found that advice regarding the benefits of change (no matter how obvious) will usually be countered when suggested by a clinician. If a person is advised to 'do this' or 'stop doing that' or 'do this instead', they will immediately come up with reasons why it will not work. 'We have tried this before and it didn't work', 'I don't have the time to implement this', 'you will never get all the house staff on board with this', 'the night shift won't do it'. This is a normal and automatic mental process, and must be dealt with carefully when eliciting change in a patient.

Confronting a person and insisting they make a change can cause the person to avoid the whole issue and stop thinking about it, which means that they have taken a step back in the 'Stages of Change' cycle from Contemplation to Pre-contemplation. So this actually causes people to be less likely to make a change. Here the clinician has 'done harm' by changing a person's view from being open to change, to being less open to change, with the clinician creating the exact opposite effect of their intent.

The point here is that unsolicited advice can send the patient backwards, making them less open to change and less likely to change. So suggestion number one is: *Try to avoid giving unsolicited advice*. Sometimes it can be so obvious and you don't understand how the patient can't see it, but pushing someone to a different point of view will cause them to become more entrenched in their own point of view and make change less likely to happen.

The amount of counter-arguments given by a person in behaviour change session *can predict a lack of behaviour change*. If you give someone advice for 5 minutes, they are counter-arguing (even maybe just in their own head) for 5 minutes. 20 minutes of advice can cause the person to counter-argue for 20 minutes. Therefore more unsolicited advice (or longer periods talking about it) can do more harm than a short mention of advice, which may still be worse than no advice at all.

Research has also shown that you can *scare* people into change (such as with a 'intervention') if you provide them with a plan on how to implement change. For example: 'If you keep drinking, you will lose your job' - scary, but won't elicit change on its own unless you can provide a specific plan (including support) to help the person stop drinking.

Arguments with clients or families will often lead to them not returning. Confrontation will cause them to stop thinking about the issue and to avoid any treatment. Research shows that this is a common problem in the field of psychology, with an almost 50% of clients dropping out of psychotherapy prematurely. One reason may be that the psychologists have been too confrontational, or have expected clients to be ready to change. Brehm's theory of psychological reactance: You pull someone in one direction and they will actively pull themselves in another direction.

Motivational Interviewing (compared to 'treatment as usual') can result in a patient being more likely to enter treatment, to stay in treatment, to complete the treatment and to attend follow-up sessions.

The Stages of Change model can also be used to help determine what is going on with patients who do not return to treatment. It is likely that they are in the Pre-contemplation stage (don't think there is a problem) or Contemplation stage (there may be a problem). Someone who does not come back to treatment is probably in the Pre-contemplation stage. Sometimes they can be pushed back into the Pre-contemplation stage if they are not handled correctly. People that finish therapy are usually in the Action stage.

MI is for people in the Pre-contemplation stage or the Contemplation stage. It can help them decide there is a problem and that it warrants fixing.

The best results occur when patients tell themselves they need to change. This is done by not telling them they need to change, but still asking them about their change. Discussion can surround the current status of the issue, why they think a change is needed, how they would go about it. The important thing is to *Listen, not to advise*. The patient decides what they want to do. Talking about it can further entrench the idea of change in the patient, leading to them being more likely to take action to make that change. The interviewer provides information to allow the patient to arrive at their own decision. The patient is the expert on him or herself. The interviewer is here to work with them, not tell them what to do. This is the fostering of *autonomy*, which is an important part of MI.

In addition to autonomy, another important process is *collaboration*. You are there to help and assist, but not to direct the process or dictate what the patient is 'supposed' to do.

Also *evocation* is important. You want to evoke change-talk, which is simply talking about change. Why they want to change, how important is it, how they want to do it, what that will lead to, etc. The more one talks about it, the more familiar the idea becomes, and as mentioned before, the idea of change can then become more entrenched. As odd as this sounds, people often do not know what their opinion on something is, until they actually *hear themselves say it*. Then it's 'out there', for public consumption. Their official opinion.

If a person begins to speak about reasons for not changing, or what is preventing them from moving forward, you can acknowledge that, but ask more about their change, why, how, etc. A patient generating reasons to not change is common, and may often be brought up spontaneously if they are ambivalent about the change, talking about both the benefits and disadvantages (pros and cons).

For a person to be a good motivational interviewer, they must be trained well. The current standard employed by ADHC is a 2-day workshop with lots of roleplays, followed by an offer of feedback by an expert motivational interviewer, if the trainee sends in audio material of their work. Research has shown that the 2-day workshop on its own is not as good as when combined with expert feedback, which leads to perfect practice. If the feedback is not expert feedback, then the practitioner does not learn the difference between perfect practice and poor practice. In general, people are poor judges of how good they are at doing things, as evidenced by the 'Above-Average Effect'. This is the universal self-reporting of being 'above average' when someone is asked how good they are at doing something, compared to everyone else.

The group was then asked to split into groups of 2 people, with an interviewer and a patient. The patient is thinking about changing something about themselves, and had to make a statement '*Something I am in two minds about changing is...*'

The interviewer had to ask 4 questions, which were:

1. *What are 2 reasons you might decide to make this change?*
2. *Tell me more about that (get them to elaborate)*
3. *On a scale of 0-10, how important is it to make this change, with 0 being not important and 10 being very important?*
4. (when the patient gives their number out of 10, the interviewer says) '*Why (patient's number) and not (patient's number minus 2)?*' for example: '*Why 8 and not 6?*' or '*Why 1 and not 0?*'

The idea of these questions is to get the person talking about change, why they want to, and how important it is. The last question addresses their level of motivation and why not less-motivated?

As mentioned before, if a person begins to speak about reasons for *not* changing, or what is preventing them from moving forward, you can acknowledge that, but ask more about their change, why, how, etc.

The last part of the talk was done by Jason Tavares who gave some practical examples of the issues addressed by David, as well as some specific strategies he used. He spoke about resistant clients, and how some well-chosen words (and more often no words at all) can make a huge difference in getting the client on board, or getting the client's support team (such as house staff) on board. Often, a strong effect can be created by just *listening*, and letting the person get out their frustrations with past interventions or past clinicians.

Motivational Interviewing is a way of being with a person based on collaboration and stresses a person's autonomy. It is a deeply empathic interviewing style which not only gathers information, but gets the patient 'on board' by them being listened to. It helps elicit the person's own reasons for change, and also ideas about how to change. By building internal motivation a person becomes more likely to engage in a particular behaviour change approach, as well as helping prepare them for treatment, which then can enhance benefits of treatment, such as completing treatment and attending follow-up.



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 venues alternate between the offices of Disability Services Australia (DSA), at Suite 5/400 Chapel Rd, Bankstown and Statewide Behaviour Intervention Service (BIS) at Building B, Level 1, 242 Beecroft Road, Epping.

Dates of meetings for the rest of 2011 are:

Mondays 24th October (DSA), 14th November (pre-conference meeting, BIS), 5th December (DSA).



Autism and Disability News

As autism cases soar, a search for clues - Unclear if rise reflects modern threats or better diagnosis

By Jacqueline Stenson MSNBC contributor, from website <http://www.msnbc.msn.com>

Once a rare diagnosis, it seems there's now an epidemic of autism sweeping the nation. Many of us know a child with the disorder, and concerned parents are searching for suspicious signs even in young babies. But while more kids are being labeled with autism, whether the condition is truly more common among today's children than past generations of youngsters is largely unclear.

There's no question that autism diagnoses are increasing, but it's unknown how much of that is due to greater awareness of the disorder by doctors and the public, a broader definition of it, a true increase in incidence or other factors.

"There is a chance we're seeing a true rise, but right now I don't think anybody can answer that question for sure," says Dr. Chris Johnson, a professor of pediatrics at the University of Texas Health Sciences Center at San Antonio and co-chair of the American Academy of Pediatrics Autism Expert Panel.

Parents who believe the disorder is increasing due to some modern threat that is damaging the brains of children have pointed the finger at childhood vaccinations and the mercury-containing preservative thimerosal that was once widely used in many of them. There are also suspicions about lead or other toxins in the environment, diet, viruses and medications. Indeed, some experts say it's possible that exposures in utero or in early childhood may play a role.

Frustrated parents struggling to cope with a disorder that seemed to appear virtually overnight understandably want answers. But clear insights are hard to come by.

Cases skyrocketing

Studies done in the 1960s indicated that autism was quite rare, affecting only about one person in every 2,000 to 2,500, according to the Centers for Disease Control and Prevention. Other research in 1970 put the figure at one case per 10,000, Johnson says.

Precisely how many people have autism today is unknown. But estimates suggest there are five to six cases of autism spectrum disorders (ASDs) per 1,000 people, says Johnson. That roughly equates to as many as one case out of every 166 people.

It's important to note that today's figures apply to the whole category of ASDs, which includes autism as well as related conditions like Asperger Syndrome and Pervasive Developmental Disorder Not Otherwise Specified. Children with these disorders have varying degrees of impaired communication and social interaction.

Diagnostic criteria changed dramatically in 1987, broadening the number of people who could be considered to have ASDs. In decades earlier, only those with severe autistic characteristics would be diagnosed with autism; others might have been categorized as mentally retarded, for example. So making comparisons across decades is difficult.

"The frequency of the diagnosis has clearly increased but that doesn't tell you beans," emphasizes Dr. William Barbaresi, a pediatrician at the Mayo Clinic in Rochester, Minn.

To get a better picture of autism and its potential causes, Barbaresi and colleagues examined new cases of autism in Olmsted County, Minn., from 1976 to 1997.

Using data on every child living in the county during those years, the researchers used modern diagnostic criteria to conclude that the incidence of autism specifically rose dramatically, from 5.5 cases per 100,000 children from 1980 to 1983, to 44.9 cases from 1995 to 1997.

A sharp increase started between 1988 and 1991, a period during which broader diagnostic criteria for autism were newly in use and increased awareness of the disorder occurred, Barbaresi says.

The findings of the study, published in the January issue of the Archives of Pediatrics and Adolescent Medicine, appear to rule out suspects like vaccinations as a cause for the increase, according to Barbaresi.

Other studies also have failed to link vaccinations to autism, prompting the Institute of Medicine, an independent group that advises the federal government, to conclude there is no connection.

But no one knows exactly what causes ASDs, and until they do, much about these disorders will remain a source of great speculation.

Many unknowns

To say that there's a lot doctors don't know about these conditions is "an understatement," says Dr. Leonard Rappaport, director of the Developmental Medicine Center at Children's Hospital Boston.

"Most things we don't know," he says.

Rappaport suspects there may be a true rise in ASDs, though he says it's not at all clear why or to what extent.

To better understand the causes, and hopefully improve diagnosis and treatment, Rappaport is involved in a new study that is focusing on genetic underpinnings of the disorders that he says may play a role in upwards of 90 percent of cases. The federal government also has organized an international coalition to explore the genetics.

Many scientists believe that ASDs are largely caused by genes. Studies have shown, for instance, that if one identical twin has autism the second twin is very likely to also have the disorder. But the risk isn't 100 percent, suggesting that other factors can contribute, even if they aren't the main cause.

"I think it's clear that there's a strong genetic predisposition," says Dr. Steve Sommer, chairman of the department of molecular genetics at City of Hope National Medical Center in Duarte, Calif.

One theory behind a cluster of cases of high-functioning autism and Asperger Syndrome in Silicon Valley holds that people who carry the genes gravitate toward high-tech professions like computer science that don't necessarily require a lot of social interaction. And when these people, who may not have the full-blown disorders, meet and have children together, the kids could be fully affected because of the double genetic whammy from both parents.

Down the line, scientists suspect they may find many genes involved in ASDs.

Sommer's research has shown that a mutation in the neuroligin 4 gene, which is involved in creating healthy connections between neurons in the brain, is defective in about 3 percent of people with autism. But that doesn't mean that everyone who inherits the defective gene will develop autism, he says. And there are likely many more genes that play a role in the condition in certain people.

"From a genetic point of view, autism is likely to be many - perhaps a hundred or more - diseases," he says.

Sleepless nights

But if autism spectrum disorders are truly on the rise, genes aren't the reason. "The gene pool doesn't change," explains Rappaport. "It would have to be something that's environmental."

That something - if it does exist - remains a huge mystery and a source of endless worry for parents, especially given that there is currently no known way to prevent autism.

Rappaport says many parents fear they may have done something to trigger the problem, like taking their kids to get regularly scheduled immunizations or exposing themselves to environmental toxins.

"Parents are searching for answers, and they're blaming themselves for a million different things," he says.

"I can't even imagine all the sleepless nights."

Disruption Of Neural Activity In Autistic Toddlers

Article Date: 23 Jun 2011

Source: Elisabeth (Lisa) Lyons, Cell Press

A new study provides valuable insight into the neuropathology of early autism development by imaging the brains of naturally sleeping toddlers. The research, published by Cell Press in the June 24 issue of the journal *Neuron*, identifies a brain abnormality observed at the very beginning stages of autism that may aid in early diagnosis of autism and shed light on its underlying biology.

The human brain is split into two separate hemispheres, which are mostly symmetrical in terms of anatomy and function. "In the typical brain, neural activity is correlated across functionally related cortical areas, like those involved in vision, not only during the completion of a task, such as watching a movie, but also in the complete absence of a task, during rest and sleep," explains lead study author Dr. Ilan Dinstein from the Weizmann Institute of Science in Israel. "It has been suggested that the strength of synchronization between functionally related brain areas in the right and left hemispheres may offer a measure of their functional integrity."

Dr. Dinstein and colleagues used functional magnetic resonance imaging (fMRI) to record neural activity in naturally sleeping toddlers with typical development, language delay, and autism and found a specific abnormality in synchronization between two brain areas commonly associated with language and communication. This abnormality was evident in 70% of toddlers with autism, but in only a handful of typically developing toddlers or toddlers with language delay. This is significant because delayed and impaired language capabilities are a defining characteristic of autism, and, although the autistic and language-delayed toddlers exhibited similar reduced language abilities, the reduced neural synchronization was unique to the autistic group.

"Our results suggest that poor neural synchronization is a notable neural characteristic that is evident at the earliest stages of autism development, when toddlers are only beginning to manifest autistic behavioral symptoms, and is related to the severity of those behavioral symptoms," says Dr. Dinstein. "It is also important to note that the ability to measure this characteristic during natural sleep, when subject cooperation is not required, suggests its utility as a possible diagnostic measure to aid growing efforts of identifying autism during infancy."

This study is part of a bigger research initiative carried out by scientists from the Autism Center of Excellence at the University of California, San Diego, headed by Professor Eric Courchesne, and was completed in collaboration with scientists at the Weizmann Institute and Carnegie Mellon University.

Pitt Study Examines Environmental Risk Factors For Childhood Autism

Article Date: 09 Jun 2011

Source: University of Pittsburgh Graduate School of Public Health

The University of Pittsburgh Graduate School of Public Health (GSPH) has launched a multi-year study to help identify environmental and other factors that may put children at risk for developing conditions within the autism spectrum disorders (ASDs). The Study of Environmental Risk Factors for Childhood Autism is being conducted throughout southwestern Pennsylvania in Allegheny, Armstrong, Beaver, Butler, Washington and Westmoreland counties.

ASDs are a group of developmental disabilities that become evident early in a child's life and cause social, communication and behavioral challenges. The Centers for Disease Control and Prevention estimates that approximately 1 in 110 children born in the United States had been diagnosed with ASDs and the rates in recent years have increased. The causes and contributing factors of ASDs are poorly understood, but genetic, environmental and biological factors are thought to be involved.

"Autism spectrum disorders are a major health concern," said Evelyn Talbott, Dr.P.H., professor of epidemiology at GSPH and principal investigator of the study. "We hope that the results of this study will help lead to a better understanding of the role of environmental factors in ASDs."

The research study involves the parents of 2- to 5-year-old children who have been diagnosed with ASD conditions, as well as the parents of children who do not have ASD conditions. Parents will be interviewed by telephone by trained GSPH staff and asked about residences, jobs, hobbies, medical conditions, medication use and other factors during the mother's pregnancy and the child's infancy. In addition, information on air pollution and other environmental exposures for each residential area will be obtained.

Researchers will then attempt to determine if there have been substantial differences in environmental and other exposures in children with an autism spectrum disorder compared to children without ASDs. Approximately 750 parents will be asked to participate in this study over the next three years.

Constance M. Bayles, Ph.D., of GSPH's Department of Epidemiology is the project director. Co-investigators include Ravi Sharma, Ph.D., Department of Behavioral and Community Health, and Vincent Arena, Ph.D., Department of Biostatistics, both of the University of Pittsburgh.

The study was funded by the Heinz Endowments.

Genes Provide Landmarks On The Roadmap Of Autism

Article Date: 09 Jun 2011

Source: Graciela Gutierrez Baylor College of Medicine

Many roads can lead to the same place, often crossing over one another and sometimes passing the same landmarks.

The interactome or protein interaction network for autism spectrum disorders developed by researchers at Baylor College of Medicine and the Jan and Dan Duncan Neurological Research Institute at Texas Children's Hospital in collaboration with scientists at the Center for Cancer Systems Biology (CCSB) at Dana-Farber Cancer Institute demonstrates how protein pathways converge, diverge and interact to arrive at the same devastating condition.

In a report in the current issue of the journal *Science Translational Medicine*, Dr. Huda Zoghbi, director of the Neurological Research Institute and professor of neurology, neuroscience, molecular and human genetics and pediatrics at BCM, and her colleagues describe the network that identifies hundreds of new interactions among proteins encoded by genes associated with autism spectrum disorder.

It also relays new information about idiopathic autism, which has no known cause. It does this by building on what is known about syndromic autism that often occurs as a symptom of a broader genetic disorder such as fragile X, tuberous sclerosis and Phelan-McDermid syndrome. The three core features of autism present in both idiopathic and syndromic cases include impaired social skills, delayed language and repetitive behaviors.

"The interactome is a more functional approach," said Zoghbi. "It can help us understand how mutations in different genes can cause similar clinical symptoms."

When the study started, she and her colleagues began with 26 genes known to be associated with syndromic autism. Studying each of those singly and devising a therapy would take a lifetime, said Zoghbi. Together, they account for no more than 30 percent of autism cases. (There are now more than 60 genes associated with autism spectrum disorder, a sign of advances in the field).

"We had these 26 genes that seemed to have little to do with each other but still resulted in autism-like symptoms," said Zoghbi. "We thought that perhaps they cause autism by interacting with some shared partners that function in pathways that lead to similar phenotypes (similar characteristics)."

They took each protein associated with autism and determined the proteins with which they interacted. The complicated network that resulted encompasses 539 proteins that interact with the 26 proteins associated with syndromic autism spectrum disorders. These protein interactions include a variety of genes including transcription factors, RNA-binding proteins, cell adhesion molecules and enzymes involved in modifying and degrading proteins.

Compiling the interactome was a massive undertaking, said Dr. Chad A. Shaw, assistant professor of molecular and human genetics at BCM and a computational scientist who was a co-corresponding author of the study.

"One of the most important contributions of this interactome is that it provides a deep, experimentally driven foundation that can be used to understand complicated genetic variation," he said.

He credits the paper's first author, Dr. Yasunari Sakai, with important work in constructing the interactome itself which Shaw and his laboratory then analyzed; Sakai also validated random selections of interactions in the laboratory, an exacting, time-consuming task. Sakai was a postdoctoral fellow in Zoghbi's laboratory.

The network confirmed many previously known or hypothesized connections and revealed previously unsuspected connectivity between two syndromic autism spectrum disorder proteins - SHANK3 (SH3 and multiple ankyrin repeat domains 3) and TSC (tuberous sclerosis protein 1).

Shaw compared the information in the network to information from published studies on chromosomal differences known as copy number variations (duplications or deletions of genetic information from chromosomes) that had been observed both in normal subjects and in patients with non-syndromic or idiopathic autism spectrum disorder. He looked for genes that were present both in their network and in the copy number variations in the individuals within the normal and autism groups.

The autism patients had a greater rate of copy number variations that included the genes in the interactome than did the control group.

The team also performed microarray or gene chip analysis for all of the genes in the network on tissue from 288 subjects with idiopathic autism collected by the Simons Foundation Simplex Collection. None of these subjects had any of the symptoms associated with syndromic autism and their intellectual capacities were fairly high.

They identified three previously unrecognized copy number variations that involve three genes found in the network, further confirming the protein interaction network as a framework for

identifying as-yet unknown causes of autism and understanding the molecular pathways that involve both syndromic and idiopathic autism.

"We are at a point in time of being able to measure people's complete genotype," said Shaw. "We can measure more variation than we can interpret. The interactome lets us tag variations to a disease-relevant network. That's why resources like the interactome are important. They help tie the complexity together. If you are trying to diagnose a person, you don't have to have a research study around each gene."

Notes:

Others who took part in the research include Brian C. Dawson, Dr. Diana V. Dugas and Dr. Zaina Al-Mohtaseb all of BCM and Dr. David E. Hill of Dana Farber Cancer Institute.

Funding for this work came from the Howard Hughes Medical Institute, the Simons Foundation and the Ellison Foundation.

Childhood Developmental Disability Rate Rose From 12.84% To 15.04% In 12 Years In USA

Article Date: 23 May 2011 - 7:00 PDT 'Medical News Today: www.medicalnewstoday.com'

In 2008 one in every 6.6 children had a developmental disability in the USA, compared to one in every 7.8 twelve years before - a rise of 17% - researchers from the CDC (Centers for Disease Control and Prevention) reported in the journal *Pediatrics*. Developmental disabilities are more common in boys than girls.

The researchers gathered and evaluated data from the 1997 through 2008 National Health Interview Surveys on kids aged 3 to 17 years. The Surveys are ongoing and are deemed to be nationally representative samples of American households.

The authors included data on the following parent-reported diagnoses:

- Attention deficit hyperactivity disorder
- Autism; seizures
- Blindness
- Cerebral palsy
- Intellectual disability
- Learning disorders
- Moderate to profound hearing loss
- Stuttering or stammering
- Other developmental delays

Below are some highlighted findings from this study:

- Boys have a higher rate of developmental disabilities than girls
- The prevalence of disabilities is lowest in Hispanic children
- The prevalence of many disabilities is higher in lower income families
- The percentage of children with a developmental disability rose from 12.84% to 15.04% over the 12-year period
- The prevalence of moderate and profound hearing loss dropped 31% over the 12-year period
- Autism prevalence rose from 0.19% in 1997-1999 to 0.74% in 2006-2008
- In 1997-1999 5.7% of children had ADHD (attention deficit hyperactivity disorder), compared to 7.6% in 2006-2008. A rise of 33%

Several factors may have played a role in the increased prevalence, the authors added.

- There are more preterm births today
- More parents are having babies at an older age
- Better and more accurate screenings and diagnosis techniques exist today

-
- There is wider awareness and less stigma regarding some developmental disorders today

The authors concluded:

"Developmental disabilities are common and were reported in ~1 in 6 children in the United States in 2006-2008. The number of children with select developmental disabilities (autism, attention deficit hyperactivity disorder, and other developmental delays) has increased, requiring more health and education services."

["Trends in the Prevalence of Developmental Disabilities in US Children, 1997-2008"](#)

Coleen A. Boyle, PhD, Sheree Boulet, PhD, Laura A. Schieve, PhD, Robin A. Cohen, PhD, Stephen J. Blumberg, PhD, Marshalyn Yeargin-Allsopp, MD, Susanna Visser, MS, Michael D. Kogan, PhD

Pediatrics doi: 10.1542/peds.2010-2989

Written by Christian Nordqvist

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Large Population Of Undiagnosed Autism In General Population According To New Brain Research Foundation Funded Study

Article Date: 23 May 2011

Source: Brain Research Foundation

A new study utilizing a population-based approach that for the first time looked for autism among all children found prevalence of the disorder to be almost three times higher than previously thought. The groundbreaking study conducted over five years in Korea by a multinational group of scientists tested all children, including those in mainstream schools who had no history of the disorder. Previous studies focused more narrowly, meaning a significant percentage of the population was never evaluated.

"This extraordinary project utilized a population-based approach that screened all the children in a large community to identify those with Autism Spectrum Disorder (ASD)," stated Dr. Bennett Leventhal, Brain Research Foundation board member and study participant. "The results of the study indicated a prevalence estimate for ASD to be 2.64% of the population; a number nearly three times previous estimates." The groundbreaking study was conducted over five years in Korea by a multinational group of scientists, led by Brain Research Foundation investigators Young Shin Kim, MD, PhD, MPH and Bennett L. Leventhal, MD.

The new study is unique in that it attempted to screen all 55,000 children ages 7-12 in a community, including those previously identified to have special needs and all children with no history of problems attending regular education classes. It is noteworthy that the previously identified children constituted 0.7% of the community and a remarkable 1.9% of the children were in regular classes without any prior diagnosis or treatment. "Prior to this new study, estimates put the prevalence of autism at one in 110 children, or less than one percent of the population," explained Dr. Terre Constantine, Executive Director of Brain Research Foundation.


This study is important because there has been concern about reports over the past four decades indicating that ASD prevalence is increasing. Some have been concerned about new causes of the disorder in the environment, however, the researchers suggest that a variety of factors contribute to the growing prevalence, not the least of which is the more thorough case finding noted in this study.

"Dr. Kim, who led the work, and our team expect the prevalence of Autism Spectrum Disorders in the United States and in other countries will be in the range of two to three percent," added Dr. Leventhal. "It is likely there are many children in our schools who have an Autism Spectrum Disorder that have not been identified and are not being provided treatment that can improve their

functioning."

The researchers emphasized that autism is a global public health concern affecting all world areas. "These dramatic results underscore how much we still have to learn about autism and the great need to increase research, especially early-stage research," added Dr. Constantine. "Dr. Kim and her entire team are to be commended, but the work to understand this disorder is just beginning."

The study was primarily funded by a grant from Brain Research Foundation with additional funding from the Institute for Ethnographic Research and Autism Speaks.



Call for Abstracts and Early Bird Registration

AADDM2012 Conference

www.aaddm2012.com

The Australian Association of Developmental Disability Medicine (AADDM) is pleased to announce that it will hold its 2012 Conference at the Scientia Centre, University of New South Wales in Sydney, Australia on March 8-10, 2012.

The AADDM2012 conference will be an *"ideal learning opportunity for medical practitioners, policy makers, academics and government,"* according to conference convenor Associate Professor Julian Trollor.

Key themes for the AADDM2012 conference are **Mental Health, Physical Health Across the Life Span** and **Health Services Development**.

International keynote speakers include **Professor Eric Emerson** (Lancaster University) and **Professor Tony Holland** (University of Cambridge) while national keynote speakers include **Professor Louise Baur** (University of Sydney), **Dr David Mowat** (Sydney Children's Hospital/University of New South Wales), **Ms Maria Heaton** (NSW Council for Intellectual Disability) and **Professor Greg O'Brien** (Disability Queensland/Northumbria University).

The AADDM 2012 Organising Committee welcomes submissions for Symposia, Free Papers and Posters. The deadline for submissions is September 26, 2011. Early bird registration closes on December 14, 2011. For more information please go to www.aaddm2012.com or contact us at aaddm@unsw.edu.au.

presents the

20th Annual Conference

Twenty Years On: Where To From Here?

November 25, 2011

Mercure Hotel Parramatta
106 Hassall St, Parramatta

General Information about Registration and the Conference

Please read this carefully

- Registration prior to the conference is **essential** (use the forms below) and will only be confirmed when payment is received. No payments will be accepted on the day.
- If your employer will pay for your registration, **please send your paperwork to them now so it can be processed and forwarded to PSYCHDD before close of registration.** You need to fill all the details of the Taxation Invoice and send it to your employer so that they can prepare payment. You also need to complete and post the **Notice of Intention** section to Emel Solak before **October 3**. This only lets us know that you wish to attend. It does not register you. You are only registered when payment is received.
- If you are paying for yourself, you only need to send in the Conference Registration/Taxation Invoice section of the form with your payment.
- This is a full day conference. Venue and other information will be provided upon registration.
- *Your registration includes on, morning tea, lunch and afternoon tea.*
- *Confirmation of your registration will be sent to you by e-mail or fax. Receipts for Payment (made to the payee) will be issued on the day.*
- **Refund policy:** Refunds for cancellations will be provided where notice is given before November 21. Refunds after this time will not be provided however an alternative person to the one who is registered may attend.

Check the PSYCHDD Website at <http://www.psychdd.com.au> for the full program during November

CONFERENCE PROGRAM INCLUDES:

- Keynote address by Keith McVilly on developments in services over the past 20 years
- Keynote address by Roger Stancliffe on future directions for clinical services
- Bullying and children with disabilities
- Issues in the use of psychotropic medication with children
- Risk assessment with adults
- Working with personality disorder and intellectual disability
- Active Support with people who have mental health problems
- End of life issues and people with disability
- Screening for Dementia in people with disability
- Person Centred behaviour support and more....

Please include with your payment if paying for yourself or forward to your Payments Officer if your employer will pay for your registration

PSYCHDD
ABN 22 404 141 513

THE ASSOCIATION OF PSYCHOLOGISTS
IN DEVELOPMENTAL DISABILITY SERVICES

CONFERENCE REGISTRATION TAXATION INVOICE

TO:

Insert name and address of organisation paying for registration

CONCERNING: payment for registration of (name)at the function identified below

DESCRIPTION	GST	AMOUNT
Registration for PSYCHDD Annual Conference on 25/11/11	Not Applicable	PSYCHDD MEMBER \$90 NON MEMBER \$110 PRESENTER free

PAYMENT OFFICER PLEASE NOTE: Cheques must be accompanied by the name of person(s) payment is being made for and must be received by **November 1, 2011**. Please make cheque payable to PSYCHDD and mark "not negotiable". Address payment to:

Emel Solak
PO BOX 3234
Redfern NSW 2016

If you have any questions concerning this invoice contact Emel Solak on 9310 2055



Please complete and post this section to the address below if your employer will be paying for your registration.

NOTICE OF INTENTION

Notice of Intention must be received by **October 3, 2011**

NAME: _____

POSTAL ADDRESS: _____

Postcode: _____

PHONE: _____ FAX: _____ E-MAIL: _____

Please indicate I am paying for my registration (payment enclosed)
 My employer will pay my registration (indicate Organisation and Region)

REGISTRATION CATEGORY: please tick

PSYCHDD MEMBER \$90 (GST not applicable)
 NON MEMBER \$110 (GST not applicable)
 PRESENTER free

PLEASE POST THIS NOTICE OF INTENTION TO: EMEL SOLAK
PO BOX 3234
Redfern NSW 2016

When and why should I renew my PsychDD membership?

Dear members,

PsychDD membership renewal is done at the conference towards the end of November every year. The cost of joining PsychDD (\$20) will be *made back by you* if

1. You attend one of the 2 big events we run every year: The Conference or the Workshop, which in more recent years has usually been held the day before the conference to allow regional psychologists to 'get more' for their trip to Sydney by allowing them to attend 2 events on consecutive days.

or

2. You attend one of the 2 forums held each year. We have made the non-member cost for forums \$20 so if you are eligible to be a member, you would now get your money back attending either of the 2 forums.

Through the year (from around March-April onwards) members are sent newsletters which contain a variety of disability-related information. Joining PsychDD later in the year will cause you to miss out on the earlier newsletters, and possibly miss our first forum (free for members) which is always held in the first half of the year (except this year it is in July, with our 2nd forum in October).

Signing up on the day of the conference will not get you the member's discount until the following conference. Depending on how late in the year you join, you may either be required to renew your membership at the conference or you may be treated as having just joined at the conference which means you won't get any PsychDD discounts until after the conference.

So



The message is: *Renew your membership at the conference or as early in the following year as you can, to get the maximum member's benefit.*

In case you are still unsure about joining or renewing your membership, consider this:

PsychDD events are worth *Ongoing Professional Development (OPD) hours*, as most of the events are organised and presented by psychologists, for psychologists.

Given that the new (national registration) rules insist that you *attend training within your field of expertise*, every psychologist working in the field of developmental disability should be a member of PsychDD.

Attending all our events should add up to around 14 hours a year (12 at the very least), which is a substantial part of your OPD requirement. If you were to write something up for the newsletter that would allow you to claim *active* CPD as well

Current PsychDD Committee

Chair:	Ewa Geba	4620 9660
Vice Chair:	John Wagner	8876 4000
Secretary:	Andrew Marynissen	9891 7202
Treasurer:	Laura Le Van	9468 7074
Newsletter Editor:	Andrew Marynissen	9891 7202
Membership Secretary:	Andrew Marynissen	9891 7202
Forum Coordinator:	Bobby Redman	1300 668 123
Conference Co-ordinator:	John Wagner	8876 4000
Workshop Co-ordinator:	Emel Solak	9310 2055
Pre-Conference Workshop Co-ordinator	Emel Solak	9310 2055
Awards Co-ordinator:	Anita Freeman	8977 8390
Webmaster:	Lorraine Teeuwen-Green	1300 372 747
Publicity:	Andrew Marynissen	9891 7202
Public Officer (incorporation):	Andrew Marynissen	9891 7202



Please consider joining our committee!!

Are You PsychDD Material? You probably are!

Our committee contains 10 people at the moment, and **there are 3 people leaving the committee over the next 12-18 months**. 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 venues alternate between the offices of Disability Services Australia (DSA), at Suite 5/400 Chapel Rd, Bankstown and Statewide behaviour Intervention service (BIS) at Building B, Level 1, 242 Beecroft Road, Epping.

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

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.

Being on the committee of an organisation of around 80 Psychologists in a specific field can be a feather in your cap when it comes to seeking work in the field. It is also favourable to the Registration Board in terms of being on the committee of a psychology-specific Association. If you become involved with our big events then you will also develop many new skills that can be applied to other areas of your work, such as organising and running groups, co-ordinating events, and becoming part of a network of psychologists.

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 (usually only email address is included):

mailing address phone number email

All members are sent flyers for events and other updates regarding events, in addition to receiving the newsletter. If you *do not* want to receive this information, please indicate by ticking the box.

I *do not* want to receive flyers, advertisements or updates regarding PsychDD issues.

Please enclose \$20.00 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, or make a comment on this form.

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