

AADDM Newsletter



Australian
Association of
Developmental
Disability
Medicine Inc.

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Advance Notice

On behalf of the local Organising Committee, Jackie Small and Julian Trollor are pleased to announce that the AADDM 2012 Conference website is now open to receive submissions for symposia and paper.

AADDM 2012 Conference will feature excellent International and National Keynote speakers, including Professor Eric Emerson, Professor Tony Holland, Professor Gregory O'Brien, Professor Louise Barr, Dr David Mowat and Ms Maria Heaton.

Key themes include but are not limited to:

Mental Health (forensic, psychopathology & phenotypes/genes, challenging behaviour, psychopharmacology);
Physical Health across the life span (primary care and forensic settings);
Developmental paediatrics;
Preventative health including obesity and metabolic disorders; **Aging and endings**;
Transition services and cutting

edge genetics) and **Health Services Development** (services structures; developments in disability health policy; continuity of services across the lifespan; education the medical workforce; Medicare locals; human rights in healthcare).

The AADDM 2012 conference encourages attendance from a wide range of disciplines including, but not limited to medical practitioners, nurses, psychologists and allied health practitioners. Furthermore, a number of bursaries are available to encourage attendance of trainees from relevant medical disciplines and carers and consumers.

www.aaddm2012.com/



President
Prof Nick Lennox

Vice President
Ass/Prof Bob Davis

Secretary:
Dr Jacqueline Small

Treasurer:
Dr Jean Graham

Editor: Miriam Taylor

Issue 15
August 2011

AADDM 2012 Conference

March 8-10
Scientia Centre,
University of New
South Wales,
Sydney,
Australia

Key dates:

Abstract submission opens
August 5, 2011

Abstract submission deadline
September 26, 2011

Notice of acceptance
November 14, 2011

Early bird registration deadline
December 14, 2011

AADDM2012 Conference
March 8-10, 2012

Elected committee members

Seeta Durvasula
Lynette Lee
Jennifer Torr

John Entwistle
Helen Leonard
Jane Law

Margaret Kyrkou
Linda Mann

Co-opted committee members

Helen Beange

Anne Kynaston

Michael Nugent



President's Report

By Nick Lennox

The focus of the executive meeting has recently been on the forthcoming AADDM conference in 2012; highlighted on the front cover of the newsletter and the AADDM endorsed Society for the *Study of Behaviour Phenotypes* conference at the Rugby Club in Brisbane on the 5-7th Oct 2011. The details can be found at www.ssbp.org.uk/site/index.php.

I am looking forward to meeting colleagues at the forthcoming events, and for me, the AADDM 2012 conference will be a good opportunity to converse face to face with friends and colleagues who share our goal of improving all aspects of health of children, adolescents and adults with developmental disability.

On the political front, we have had discussions with the Hon Mark Butler (Minister

responsible for Mental Health) and with Senator Jan McLucas (the Hon. Secretary for Disability) about the apparent omission of specific funding for people with intellectual disability within the mental health funding announced at the most recent budget. We have also made a joint submission to the Senate enquiry into this mental health funding. As a consequence of our meetings with the Department of Health and Aging, we have seen people with disabilities included in the early pilot implementation of the Personally Controlled Electronic Health Record (PCEHR) and funding provided to the Council on Intellectual Disability to improve the responsiveness of the new Medicare Locals to the needs of this population.

Overall, we have seen great responsiveness to the issues we raise and feel the position statement that the NSW CID and AADDM have developed

has been a useful catalyst for change. If you have eminent Australians whom you could approach to sign the statement, then please discuss this with them. The most recent version of the document is on our website:

ausaddm.wordpress.com/home/

One highlight for me over the last year has been discussions with Jayne Lehmann, who is a diabetic nurse educator and parent who has been doing some great work in Adelaide. She describes some of her inspirational activities in this newsletter.

Finally, Jim Simpson has been unanimously nominated by the executive to be the first Honorary member of AADDM for his contribution to improving the health of people with intellectual disability through advocacy. He has worked positively with AADDM over many years to help embed many of the changes we have made to the national health policy, NSW health policy and practice across Australia. His well prepared, thoughtful, calm and persuasive style has been very welcome by colleagues, and by those inside and outside government. Thank you and welcome Jim—you are an inspiration to us all!

Best wishes to all,
Nick





Diabetes Assessment and Education Clinic for People with Intellectual Disability

Diabetes is affecting more and more people with intellectual disability and creating many challenges for health services caring for people with intellectual disability.

A complex condition, diabetes can be very difficult to care for in the intellectual disabled because of the need for both lifestyle and medical review. Many do not achieve the generally accepted diabetes health targets of diabetes management, creating poorer health outcomes for the individuals concerned.

It is therefore surprising there have not been more services designed to address the needs of people with diabetes who are intellectually disabled in Australia.

Jayne Lehmann, a Credentialed Diabetes Educator in South Australia, introduced a Diabetes Assessment and Education Clinic for people with intellectual disability at disability organisation Minda in early 2010. Minda provides a range of support services to approximately 1500 people with intellectual disabilities in the Southern suburbs of metropolitan South Australia (SA),

including the monthly clinic on the Brighton campus.

The aim of the Clinic is to assess each person's current diabetes health and empower them to be actively involved in their day-to-day diabetes care.

Jayne explains, "One of the clients attending the Clinic is now doing his own blood glucose monitoring and insulin injections using a pen



after having had carers do them both for years. He has been a real success story, especially because of his pride in his achievements."

Jayne combined her diabetes management and education skills with the knowledge and skills gained from caring for her 17 year old intellectually disabled daughter who lives with Dravet Syndrome, to create a unique clinical service.

Focussing on the practical side of diabetes care, Jayne provides each client with a

Diabetes Health Plan and list of suggestions negotiated with the client and carer during each session to facilitate their diabetes care. This information is then shared with the general practitioner and other health team members.

Jayne said, "I have been tracking the glycosylated haemoglobin (HbA1c) of clients from the time they are referred and nearly all clients have had a drop in their HbA1c. A few have also had a sudden HbA1c rise but we have been able to review them more intensively to get them back on track sooner.

A range of new resources were developed from funds secured from the Novo Nordisk Regional Diabetes Support Scheme in 2010. They have been trialled in the clinic and help to support staff to implement the actions identified during the clinic. Jayne explains, "The clinic was a natural extension of the work I had been doing in South Australia for some years."

Jayne has previously designed a Diabetes Care Strategy for Disability SA (a government service for people with intellectual disability in SA) a diabetes care manual, conducted education sessions



Cont from page 3

and reviews complex clients with diabetes on behalf of disability organisations.

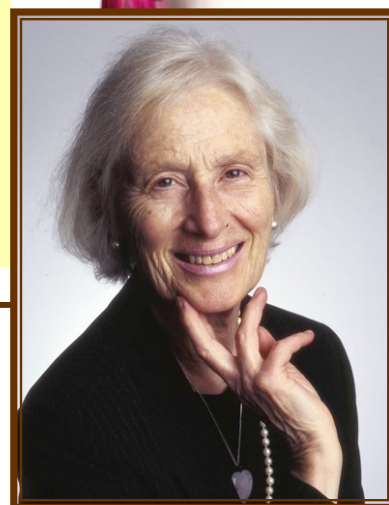
A recent service evaluation identified the carers and parents who had attended the clinic felt diabetes care had significantly improved since the clinic began and clients were happier with their diabetes. Jayne will be presenting this work at the Australian Diabetes Society and Australian Diabetes Educator's Association Annual Scientific Meeting in Perth at the end of August and at the Australasian Society for Intellectual Disability in Adelaide in November.

Jayne was also awarded the 2010 Peter Edwards Memorial Award for her ongoing contribution to the



intellectual disability sector as a parent, advocate and educator. As a result a camera and computer program to utilise in the clinic has been purchased to further support clients in their diabetes education.

Please contact Jayne Lehmann at jayne@edhealth.com.au if you would like to hear more about her work or to share information on the care of people with intellectual disability and diabetes.



Obituary: Dr. Barbara Starfield

Dr. Barbara Starfield, a professor and health services researcher at the Johns Hopkins Bloomberg School of Public Health whose work in the field of primary care and health policy brought her international acclaim, died on June 10 while swimming at her home in California at the age of 78.

Her great knowledge of and

advocacy for primary healthcare is legendary.

Here is one of her quotes to inspire you:
"It is time that primary care physicians take leadership in moving medical care where it needs to be: to the care of patients and populations and not the care of diseases. It is not only biologically correct

to do so - it is also more effective, more efficient, safer, and more equitable."

From *The hidden inequity in health care* in the International Journal for Equity in Health 2011, 10:15
[doi:10.1186/1475-9276-10-15](https://doi.org/10.1186/1475-9276-10-15)



Press Release from Endeavour Foundation

Data collection on people with intellectual disability is so poor in Australia that health planners have little idea what the future holds.

“The Australian Institute of Health and Welfare estimates there are between 300,000 and 500,000 Australians with an intellectual disability, and we do know that they shoulder an unequal share of the health burden,” Endeavour Foundation CEO David Barbagallo said.

“The lack of data means that despite the promise of improvements through national reform, the health system is ill-prepared for the challenge which lies ahead,” Mr Barbagallo said.

There were about 1.4 million Australians with a disability and this would balloon to about 2.5 million people by 2040.

“We can no longer ignore this issue and hope it goes away. The system badly needs fixing and the cost of doing nothing will be even more,” Mr Barbagallo said.

“The Productivity Commission has handed a simple solution to the

federal government, in their final report on a National Disability Insurance Scheme (NDIS). If the final report mirrors the draft report then there is a clear plan to fix the problems in the disability sector,” he said.

Researchers indicate many people with intellectual disability experience ageing-related illnesses much sooner than other members of the general population.

Australia has very few research centres specifically dedicated to the physical and mental health of people with intellectual disabilities. Head of the Queensland Centre for Intellectual Disability (QCIDD) Professor Nicholas Lennox says the NDIS would address many of these issues.

“The provision of adequate care and support would deliver guaranteed health benefits for people with disabilities and carers,” Professor Lennox said.

“Personal hygiene, healthy eating, exercise and social interaction would be boosted under the proposed NDIS, and we all know these are basic keys to good health for everyone,” he said.

“People with both physical and intellectual disabilities may need extra support to get the kind of exercise they need for good health and strength. Support may be needed for people with disabilities to get out and enjoy social interaction.

“And we don’t need to develop a fancy program to gain health benefits through these simple improvements.

“It’s obvious to me as a doctor that better support in these four basic areas would deliver big health benefits for people with disabilities, in turn reducing pressure on the health system.

“The government – and the nation – can’t afford to ignore the NDIS. Every Australian with a disability should have the right to adequate care and support, and that’s exactly why we need the NDIS,” Professor Lennox said.

reducing long-term costs for everyone.

Continued over

Mr Barbagallo said early intervention would deliver better outcomes for many people with disabilities,

“The Productivity Commission says the costs of the NDIS are ‘manageable and justified when taking into account Australia’s wealth (and) economic growth’,” Mr Barbagallo said.

“This universal national plan, akin to Medicare, would meet the care and support needs of all Australians with a significant disability, regardless of how or when their disability came about. It’s a concrete, practical initiative with economic rigour, careful planning and real-world road-testing at its core,” he said.

“The reality is that anyone can acquire a disability in a moment. That makes the NDIS of clear benefit to all Australians. Currently each state and territory has different disability support and funding arrangements, and there is no recognised entitlement to funding or services for people with a disability.

“The plan would give assurance to ageing carers who worry what will happen to their child, sibling or spouse with a disability after their death. And people wouldn’t have to move interstate - or worse, overseas - to get the basic disability support funding they need.

“Australia needs to offer a fair go for people with a disability, their families and carers,” Mr Barbagallo said.

WHAT DO WE KNOW?

- There is gross under-reporting of the number of people with intellectual disability in Australia.
- Adults with intellectual disability will have, on average, five concurrent health issues. Only two or three will be diagnosed.
- The population of people with intellectual disability is ageing; like the rest of the population they are living longer than ever before.
- Researchers think many people with intellectual disability experience ageing-related illnesses much sooner than other members of the general population.
- The usual effects of ageing may also be compounded by a syndrome such as the early onset of hearing loss, heart disease and dementia which often occurs among people with Down Syndrome.

We know that connectedness is a key indicator of health outcomes, and that people with a disability have a low rate of connectedness, and consequently experience worse health on a range of indicators, not only mental health indicators.

Endeavour Foundation is one of Australia’s largest non-government providers of services for people with a disability.

They provide accommodation, education, training, employment and lifestyle opportunities for more than 3,350 people

with a disability across Queensland and in Sydney

to help them lead an ordinary life.



**AADDM & NSWCID
SUBMISSION TO SENATE COMMUNITY AFFAIRS REFERENCE
COMMITTEE (Summary)
on
THE GOVERNMENT'S FUNDING AND ADMINISTRATION OF
MENTAL HEALTH SERVICES**

The problem

People with intellectual disability have very high rates of mental disorders. However, diagnosis is very challenging. Many people with intellectual disability have limited verbal communication and experience an atypical presentation of mental disorders.

Research shows very poor access to mental health services for people with intellectual disability and a mental illness. Psychiatrists and GPs see themselves as inadequately trained to treat this group.

Mental disorders are frequently not recognised or are misdiagnosed and inappropriately treated.

In Australia, there are only isolated pockets of expertise in intellectual disability mental health. In England, there is a well developed specialty in intellectual disability mental health.

What we seek

The needs of people with an intellectual disability and a mental disorder should be specifically considered and accommodated in all mental health reform. In Part B of this submission, we set out how this should be done in relation to current Commonwealth reforms.

All funding of mental health services should include a specific requirement that the services will provide equitable access and appropriately skilled treatment to people with intellectual disability.

The government should fund a network of specialist intellectual disability mental health psychiatrists, nurses, psychologists and other professionals. These professionals would act as a consultancy, training and research adjunct to mainstream mental health services.

Enhanced joint planning by disability services and mental health services including development of a mandated shared case coordination capacity where intellectual disability and mental disorder co-exist.

Mandated training in intellectual disability mental health to minimum standards for front-line and other professional staff in disability services and mental health services.

The core aspects of our views are summarised in our proposition below, which has been circulated since late February, 2011, and has been endorsed by key stakeholders in mental health and intellectual disability.

Proposition

People who have both an intellectual disability and a mental illness need to be included from the start in mental health reform. They currently have very poor access to appropriate mental health services.

Government needs to address this problem, in particular by funding specialised intellectual disability mental health psychiatrists and nurses who can act as a consultancy, training and research adjunct to mainstream mental health services.



Update on the National Disability Insurance Scheme NDIS

www.fahcsia.gov.au/sa/disability/pubs/policy/way_forward/Documents/national.htm

A NDIS would provide a lifetime approach to care and support for people with disability and would replace the current arrangements for funding specialist disability services.

A social insurance model is proposed. It would assess the risk of disability in the general population; calculate the costs of meeting the essential lifetime needs arising out of these disabilities; and estimate the premium or contribution required from taxpayers to meet these needs.

Instead of funding capped programs and services for people with disability to find and access, the scheme would fund on the basis of each individual's needs which would in turn drive the development of

necessary care and support services.

The costs of a NDIS could be funded from general revenue or through a Medicare-like levy. Implementation should be staged over 7 to 10 years to enable new service infrastructure and workforce to develop, and to balance the constraints of the medium-term fiscal outlook against intergenerational trends.

The scheme would cover the existing eligible population under age 65 years when the scheme starts as well as people who become eligible in the future.

Who would be eligible?

- ♦ People with a severe or profound disability acquired before 65 years of age would be eligible for life. People with a severe or profound disability are those who always or sometimes need help

with a core activity or task.

- ♦ Carers would also be recognised and supported in their roles and opportunities to combine caring and work would be encouraged.
- ♦ People who are covered by state/territory-based accident compensation schemes would continue to be covered by them, however, the interaction of these schemes should be further investigated.

What services and benefits would people receive?

Coordinated services based on need would provide care and support including respite, aids, equipment, transport, home modifications and a range of community and day programs.

Other support funded



outside the scheme such as income support, housing and employment services would be integrated to provide support and opportunities for people with disability as part of a holistic approach.

There would be an emphasis on early intervention and access to education and training to maximise long-term independence and potential.

A NDIS would operate under a new National Disability Commission, possibly a statutory authority, with a formal and independent governance model comprising a prudential board of directors to oversee the operation of the scheme and an advisory council of stakeholders to provide policy advice on the appropriateness and quality of the benefits.

AADDM aims

The aims of AADDM are to:

1. Improve the health of people with developmental disability across the lifespan;
2. Establish a national standards for management of the health of people with disability;
3. Endorse a national approach to delivery of health care in Australia for people with developmental disability;
4. Continue professional development of doctors with an interest in the health of people with developmental disability.

AADDM has adopted as its Principles the **European Manifesto: Basic Standards of Healthcare for People with Intellectual Disabilities**, which are driven by principles of human rights. This Manifesto states that:

- ☐ People with intellectual disabilities are citizens of their country and they have an equal right to be included in society, whatever their level of disability.
- ☐ People with intellectual disabilities have many gifts and abilities, but they may also have special needs and may need a choice of services to support their needs.
- ☐ People with intellectual disabilities have the same human rights as other citizens.
- ☐ People with intellectual disabilities have the right to equal participation in society and to participate in all decisions that concern their lives.

*Interesting websites
(Just CLICK on
links)*

<http://www.bbc.co.uk/news/health-13925333>

<http://www.bbc.co.uk/news/health-13309756>

<http://www.abc.net.au/rn/healthreport/stories/2011/3167686.htm#transcript>

<http://www.abc.net.au/rn/healthreport/stories/2011/3186166.htm#transcript>

<http://www.abc.net.au/rn/healthreport/stories/2011/3125328.htm>



Upcoming conference

Abstract submissions are now open, visit the conference website at <http://ihcrc.yrd.com.au/>

6th and 7th MARCH 2012
The Stamford Plaza Hotel • Brisbane Queensland Australia

4th PRIMARY HEALTH CARE REFORM CONFERENCE

International Innovation, Policy setting and Research

TOPICS

- Clinical models of care
- Policy development
- Health care governance
- Change adoption

- Primary care innovation and reform
- Primary care health services research
- E-health across sectors
- Clinical microsystems methodology
- Professional development / teamwork

KEYNOTE SPEAKERS

- Prof Martin Roland (UK)**
Prof Health Services Research University of Cambridge
- Dr Paul Grundy (USA)**
IBM's Global Director of Healthcare Transformation
President, Patient-Centered Primary Care Collaborative
- Prof Mukesh Haikerwal (Aust)**
Chair, World Medical Association
and Clinical Lead NEHTA
- Dr Harry Pert (NZ)**
President RNZCGP and founder
Rotorua General Practice IPA
- Dr Donald K T Li (HK)**
Regional President,
Wonca Asia Pacific
- Conference Chair**
Prof Claire Jackson
University of Qld

Abstracts for paper and poster presentations

The Conference Planning Committee invites clinicians, researchers, consumers, policy makers and health care organisations to submit abstracts for brief presentations or posters that reflect the themes above. Abstract submission closes on Friday 28th October. To submit an abstract visit the conference website www.ihcrc.yrd.com.au

The conference will bring together primary care organisations, researchers, policy makers, consumers and clinicians from Australia, NZ, Europe, the Asia Pacific and North America to build the reform platform for primary care globally and create a network for future growth

FOR MORE INFORMATION on the IHCRC please email ihcrc@yrd.com.au