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THE UNIVERSITY  
OF QUEENSLAND

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Our aim is to improve the health and wellbeing of adults with a developmental disability in Queensland, through multi-disciplinary research, education and clinical practice.

## Family Forum:



## Friendships, Relationships and Resilience

Thursday 18th February 2010 from 9am to 3:30pm

Des O'Callaghan Theatre, Mater Hospital, South Brisbane

Registrations open in late November

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### In this issue:

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### Welcome to Jodie Carter, our new Psychiatrist

Jodie is stepping in for Cathy Franklin during her absence and will be providing psychiatric assessments and management plans on Wednesdays.

### Welcome to John McAuley,

John is 4<sup>th</sup> year Psychiatric Registrar and is providing psychiatric assessments and management plans Wednesdays/Fridays under Nick's & Jodie's supervision until January. John is a keen musician and competes in motorsports.



## ***A Healthier Future for All Australians***

The AADDM and NSW CID submission to the National Health and Hospitals Reform Commission (NHHRC) was referred to directly in the final report of June 2009, *A Healthier Future for All Australians* highlights the need for a national focus on this population:

3.2 *Access to specialist medical services is also a major gap to be addressed for **people living with an intellectual disability**.*

4.1.3 *We want to stress the value of prevention, health promotion and early intervention regardless of people's age, health status or disability. It is important that everyone – including... **people with an intellectual disability**... – is given the opportunity to achieve their maximum health potential.*

### **RECOMMENDATION 18**

We recommend that young families, Aboriginal and Torres Strait Islander people, and people with chronic and complex conditions (including people with a disability or a long-term mental illness) have the option of enrolling with a single primary health care service to strengthen the continuity, co-ordination and range of multidisciplinary care available to meet their health needs and deliver optimal outcomes. This would be the enrolled family or patient's principal "health care home". To support this, we propose that: there will be grant funding to support multidisciplinary services and care coordination for that service tied to levels of enrolment of young families and people with chronic and complex conditions; there will be payments to reward good performance in outcomes including quality and timeliness of care for the enrolled population and over the longer term, payments will be developed that bundle the cost of packages of primary health care over a course of care or period of time, supplementing fee-based payments for episodic care.

### **RECOMMENDATION 24**

We recommend that universal child and family health services provide a schedule of core contacts to allow for engagement with parents, advice and support, and periodic health monitoring (with contacts weighted towards the first three years of life). The initial contact would be universally offered as a home visit within the first two weeks following the birth. The schedule would include the core services of monitoring of child health, development and wellbeing; early identification of family risk and need; responding to identified needs; health promotion and disease prevention (for example, support for breastfeeding); and support for parenting. Where the universal child and family health services identify a health or developmental issue or support need, the service will provide or identify a pathway for targeted care, such as an enhanced schedule of contacts and referral to allied health and specialist services. Where a child requires more intensive care for a disability or developmental concerns, a care coordinator, associated with a primary health care service, would be available to coordinate the range of services these families often need.

To read the full report, please go to <http://www.nhhrc.org.au/internet/nhhrc/publishing.nsf/Content/nhhrc-report>

### *Launch of Healthier Lives – pathways to better health for people with intellectual disability*

**Keynote Speaker—Associate Professor Nick Lennox—Director Queensland Centre for Intellectual and Developmental Disability & President of the Australian Association of Developmental Disability Medicine**



Nick launched the new fact sheets on better health for people with intellectual disability developed by the NSW Council for Intellectual Disability .

The NSW Council for Intellectual Disability (NSW CID) is a peak body representing the rights and interests of people with intellectual disability in NSW. The Council takes on such activities as providing policy advice, systemic advocacy, community education, and information provision and dissemination. NSW CID has an information service and resource centre providing information to people with intellectual disability, their families, carers, advocates and service providers. NSW CID is committed to the principles of inclusion and participation and we aim to ensure people with intellectual disability are included in every aspect of the work we undertake.

<http://www.nswcid.org.au/>



## Visitors to QCIDD

Professor Doune Macdonald and Dr Sean Tweedy from the Bachelor of Applied Science (Exercise and Nutrition Sciences) to talk about research and collaboration on increasing healthy activities for people with intellectual disability.

Dr Gita Sarda, the Year 1 MBBS Course coordinator, School of Medicine, to talk about how we can increase our involvement in teaching undergraduate doctors.

Dr Genevieve Giuliani of Uniquet to discuss the conversion of the CHAP into electronic format.

Professor Jill Wilson, School of Human Services at the University of Queensland to discuss how we expand social work student involvement in the centre.

Oral health interest group to write a position statement about the oral health of people with intellectual disability.

Dell Hele, Miriam Taylor, Henny Lantman, Nick Lennox at Mt Coot-tha

Dr Henny Lantman, visiting Professor of General Practice from The Netherlands presented twice on: *Towards inclusive health care for persons with intellectual disability—General practice based research on health and health care of persons with intellectual disability in the Netherlands*. She was well received and we valued her visit. We have been speaking with Dr Lantman about other ways we can collaborate with her and the University of Maastricht in the future.

## Successful grants

### The transition of young people with intellectual disability from school to adulthood

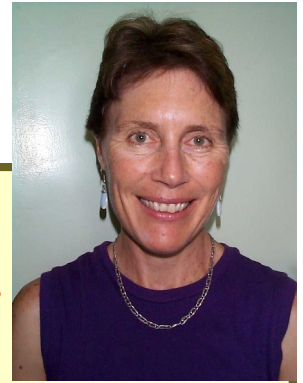
This is a project funded by an ARC Linkage Grant from 2009-2013 in collaboration with The University of Western Australia, the Telethon Institute for Child Health Research, the University of Sydney, Monash University, Curtin University of Technology, Disability Services Commission Western Australia, Western Australian Department for Education and Training and the Down Syndrome Association of Western Australia.

*In September, we held a Spring High Tea to say thank you to our supporters. Many came and many couldn't, so we just want to say THANK YOU to our friends and supporters for all your help and collaboration over the past year.*





## Staff Profile Dr Gillian Eastgate



Congratulations to QCIDD'S Dr Gillian Eastgate who is also a Bond University (Primary Health Care Novice Research Fellow). Gillian won an award for the best first-time presentation at the GP&PHC Research Conference in Melbourne in July 2009.

Gillian is undertaking a project at the moment about sexual abuse knowledge and protection skills in women with intellectual disability. Here she describes the project:

In my clinical work I frequently see women with intellectual disability who have experienced sexual abuse. Many display emotional, behavioural or mental health problems, all known sequelae of sexual abuse. These problems increase the difficulty of supporting these women. I hope this study will help raise awareness of the issue and stimulate debate about improved supports and services. I will be using a semi-structured narrative interview with women with mild intellectual disability about topics including 'sexual literacy', sexuality education received, positive and negative sexual experiences, instances of abuse and self-protection skills, and using the qualitative analysis program NVivo to analyse the data. So far, I have found varying levels of 'sexual literacy' from no concept of sexual intercourse to extensive sexual knowledge. Five out of six participants reported at least one unwanted sexual experience. All described their abuser as someone known to them. Three reported repeated, severe abuse. Three had reported their experience to someone else. Only one had received an appropriate response. Four participants reported sexual difficulties including avoiding all physical contact, vaginismus and lack of sexual pleasure. None of the women could describe consistent self-protection strategies.

To be continued...



### *The Passports to Health Project - (Stuart Kinner & Nicholas Lennox)*

Prisoners released into the community can experience a range of social, physical and emotional problems, and they have a high risk of premature death and many will return to prison within the first two years. A large percentage of the prison population is people with intellectual disability, although because not all prisoners are screened for intellectual disability, the exact percentage is not known. The purpose of this project is to find out more about the experiences of men and women once they are released, such as finding employment and accommodation, physical and mental health, substance use, and how they use health and community services. We are also interested in getting information about those who return to prison. In this randomised controlled trial, participants will receive one of two interventions, and results will be compared at the end of the study. As of 11 June 2009, 607 participants have agreed to be involved in the project (38% of total needed). Of the many problems faced by ex-prisoners, stable and affordable accommodation is a major factor in improving post-release outcomes and reducing the risk of re-offending. In our study, accommodation was seen as extremely important. When asked about living arrangements following their release from prison, only 10% stated that they had no plans, 28% staying with family (mainly parents), 12% staying with friends and 26% going into share accommodation. Research shows that prisoners' expectations do not always match the reality of post-prison life. We will be able to see how well participants were able to maintain stable and consistent living arrangements, which may be an important predictor of successful integration into the community.

# OUT OF THE SHADOWS

COMMUNITY LIVING PROGRAM AND VICTIMS OF CRIME DISABILITY TRAINING PROGRAM

## PAPER BAG LUNCHES

It has become increasingly obvious in the work that is done by CLP and VOC that the issues that complicate life for people with intellectual disabilities are absent from social debates and practice approaches. At the present moment most people with intellectual disability are the invisible people in the disability sector—yet they in fact make up a substantial percentage of the population. In an effort to address this invisibility we are inviting you to attend a series of paper bag lunches that will expose gaps in practice which make people with intellectual disability vulnerable and at risk of system abuse and system failure.



Shelia Smart 2006

Our organisations have a history of practice and research that informs our knowledge about practice to work in holistic approaches with a person and their environment which we wish to share with the wider community as a means of advocating of appropriate service responses to people.

The lunches provide a forum for discussion at both theory and practice levels to enable anyone working with a person with an intellectual disability to develop a tool box of knowledge and skill. In doing this our hope is that generic organisations are more able to respond to a person's individual difference by being aware of the complex web of constructs that make up people.

To Book Call—Sandi on 3862 4066 or email [sandi.voc@wwild.org](mailto:sandi.voc@wwild.org)

### Discussions

Making People Up! How the past informs our current treatment of people labelled as intellectually different

Community Living Program—talking about

Relationships and Roles—what makes for a good life—what gets in the way of one.

Understanding Vulnerability and how Communication play a role.

Pathways to Prison

Dual Diagnosis—intellectual disability and mental illness

Self Soothing what people do to ease the feelings of difference and stigma.

### Where and when

24th September 2009  
WWILD 211 Hudson Rd, Woolloowin 4030

26th November 2009  
WWILD 211 Hudson Rd, Woolloowin

28th January 2010  
QCIDD Corbett Room Level 1 Mater Hospital

25th March 2010  
WWILD 211 Hudson Rd Woolloowin

27th May 2010  
QCIDD Corbett Room Level 1 Mater Hospital

29th July 2010  
WWILD 211 Hudson Rd Woolloowin

23rd September 2010  
QCIDD Corbett Room Level 1 Mater Hospital

### Cost

Sessions are \$20.00 and include a paper bag lunch provided by the Express Train Café, Nundah .... Please indicate your dietary needs when you book for the session.

**Time—11.30am —1pm**

QCIDD is hosting the sessions in January, May, and September.



## Introducing a new student who will be working with QCIDD until the end of 2009: Anthony Noonan

Originally from country WA, Anthony moved to Sydney and has worked in finance and upholstery. He relocated to South East Queensland as a credit manager for a mortgage management company but due to the economic crisis, he left on redundancy. Anthony then reconfigured his life and found work with people with disability, a job he had always wanted to do. He has worked as a lifestyle support worker now for years. Anthony says: "Being in this environment has given me great insight into the lives of these individuals. The way in which disabled people live their lives today, has changed considerably in most areas. Continual improvement in some areas is still needed and this is why I have taken the opportunity to study so I can further enhance the lives of these individuals and work towards providing them with lifestyle opportunities that I take for granted." As part of his current studies for a Diploma of Community Welfare, Anthony has elected to further research the areas of support services and places of residence available to gay, lesbian, bisexual, transgender and intergender (GLBTI) individuals with disability. With the support and assistance of QAHC - Queensland Association of Healthy Communities Inc. and QCIDD - Queensland Centre for Intellectual & Developmental Disability, Anthony is now seeking community engagement and communication with other individuals, groups or organisations that currently provide a service who are interested in the development of this field. The information will be collated and used in the development of educational and training material for QAHC and QCIDD to further assist the broader community in understanding the needs of GLBTI individuals with disability. By creating greater awareness and the bringing together of support networks, it will enable us as a community to improve the rights for GLBTI individuals with disability to express and experience the life that they choose and deserve. If you would like to communicate further on this subject, please contact Anthony via

[tumbletop@iprimus.com.au](mailto:tumbletop@iprimus.com.au)



# SEEKING EXCELLENCE

**45th ASSID AUSTRALASIAN CONFERENCE**  
29 September - 1 October 2010  
Hilton Hotel, Brisbane

Co-sponsored by AADDM and CEBS

For more information contact:  
[assid2010@optusnet.com.au](mailto:assid2010@optusnet.com.au)  
[www.assid.org.au](http://www.assid.org.au) or 07 31632496



**CALL FOR ABSTRACTS:**

**9 November 2009**

**REGISTRATIONS OPEN:**

**9 November 2009**

**Abstract deadline:**

**1 March 2010**

**Early Bird Registration closes 30 June 2010**

**Standard Registration closes 31 July 2010**

**Late Registration from 1 August 2010**

**For more information contact:**

**[Assid2010@optusnet.com.au](mailto:Assid2010@optusnet.com.au)**

**or (07) 3163 2496**

# HAPPENINGS

We held clinics on Fragile X Syndrome and Prader Willi Syndrome in the last three months.

Nick received the prestigious Eric Elder Medal from the Royal New Zealand College of General Practice for his service in primary care to people with intellectual disability. He gave the keynote address at the recent RNZCGP conference on Primary Care and also presented to the NZASID Conference on health and people with intellectual disability.

Lisa presented to the UQ Social Work Masters students, to the Australasian Bioethics Association, and to the ASSID State Conference.

Madonna attended the QAI presentation by the Office of the Senior Practitioner about Victoria's Restrictive Intervention Data System (RIDS).

Miriam presented to the Family Planning Queensland Conference to celebrate 21 years of sexuality education in Queensland and to the MBBS Forum on Sexuality for Year 2 medical students.

John presented to the Darling Point Special School.

## Our latest publications

**Lennox N, Edie G, Taylor M, Rey-Conde T, McPhee J. Diabetes - To the Point: Designing a website about diabetes for adults with intellectual disability and their carers. *Technology and Disability*. 2009;21:1-8.**

In this paper we describe the development and evaluation of a resource for people with diabetes and intellectual disability and their care providers. The development process involved extensive consultation with people with intellectual disability, care providers, and a variety of allied professionals (n=76) through 39 focus groups discussions. Content analysis was undertaken and the resource developed into two formats: a booklet and a website with two target audiences: the person with intellectual disability and the care provider. The evaluation of the resource was then undertaken over one month with 14 people with intellectual disability and 31 care providers. Responses to the resource contributed to the final design. The resource in both formats was well received by both people with intellectual disability and their care providers. One third of care providers changed their behaviour in a wide range of areas of diabetes care after using the resource for a short time. The consultative process used resulted in greater resource acceptability and uptake of information about diabetes management..

**Lennox N, Rey-Conde T, McPhee J, Taylor M. The development and evaluation of resources about Diabetes management for people with intellectual disability and their care providers. *Journal on Developmental Disabilities*. 2009;15(2).**

In this paper we describe the design of a website based on written information about diabetes for people with intellectual disability and their care providers. The design process was collaborative with adults with intellectual disability, care providers, and professionals. The design followed the *W3C Guidelines – Accessibility Guidelines Double A*. Preliminary results are promising and the site is having about 850 pages accessed per month. The consultative and design processes used resulted in a unique and acceptable educational tool for people with intellectual disability who have diabetes and their care providers.