



March 2009

Vol2 Issue 1

QCIDD Information Day

Tuesday 28th April 9:15am-4pm (registration opens at 8:45)

Des O'Callaghan Theatre at the Mater Hospital, South Brisbane

Dr Jennifer Galstuch-Leon Presents

"Mental Health and Intellectual Disability"

Information about how the mental health system works and how to access that system; An overview of psychopharmacology and mental health treatment; A review of common medications used as treatments in challenging behaviour; Physical Health and Behavioural phenotypes.

To request registration forms, please email qcidd@uq.edu.au

Dr Galstuch-Leon is currently a psychiatry registrar working at QCIDD. After graduating as a medical doctor from the University of Chile in 2002 she trained as a Psychiatrist at the University College of London. Her main research involvement has been in a psychiatric epidemiological research project, evaluating the Healthcare unit development at Pentonville Prison, in North London, UK. In addition to her clinical work she has been actively involved in the provision of psychiatric teaching of medical students and second contents and second contents are second contents. In addition to her clinical work she has been actively involved in the provision of psychiatric teaching of medical students and S medical residents.

Comprehensive Health Assessments available

Disability Services Queensland (DSQ) is making available an easy to use Comprehensive Health Assessment Program (CHAP) to enable improved identification and documentation of health needs of adults with an intellectual disability. CHAP is available to every adult with an intellectual disability in Queensland who receives a DSO delivered or funded service. CHAP has been developed by the Queensland Centre for Intellectual and Developmental Disability as a two-part book. This book can be downloaded and completed by individuals, family members, carers, general practitioners and staff of government and funded non-Government service providers on behalf of a person with an intellectual disability.

For more details, please go to http://www.disability.qld.gov.au/support-services/providers/chap/ Or contact DSQ Service Access Community and Funding on 32473562.



Medicare health checks reveal hidden suffering!

Jim Simpson, NSW Council for Intellectual Disability

GPs around Australia are reporting great results from using the annual health assessments of people with intellectual disability that are now covered by Medicare. From July 2007 to December 2008, 8,700 people with intellectual disability had assessments.

Hobart GP Nick Cooling reports often finding up to three previously untreated conditions when doing the assessment. These include reflux, tooth decay, skin cancers, side effects from medication interactions, excess ear wax and various visual problems. Dr Cooling suspects that the assessments will be of greatest use for detecting the less acute conditions which may have long term consequences if not treated early. Dr Bob Davis is Director of the Centre for Developmental Disability Health in Melbourne. He also works in a general practice. Even with his expertise in intellectual disability, Bob is finding that the new assessments are helping him to pick up important health problems. For example, he recently found that a patient had an inflamed oesophagus – the assessment had revealed that the patient often wakes up quite distressed and then settles with a glass of milk. An Adelaide woman who was thought to be "uncooperative" was found to have significant hearing loss. She now has hearing aids and her first word after they were fitted was "Birdies!" – it was a long time since she had heard birds cheeping. Another woman was found to have a serious malignant cancer which is now being treated.

Are people you know getting the benefit of the Medicare assessments?

You can ask the GP to do the assessment. In their busy practices, GPs will not all be aware of the assessments or think to offer them. When making the appointment, explain that you are seeking an assessment under Medicare item 718 and request a long appointment. If the assessment needs to be done at the patient's home, the GP can charge extra under item 719. Take the person's medical records and current medications to the assessment. If possible, someone who knows the person well should attend the appointment to help provide the information the doctor needs.

In Queensland, as in Victoria, NSW and Western Australia, Disability Services have offered each service user with intellectual disability the use of a Comprehensive Health Assessment Program (CHAP) which can be used as part of the Medicare assessment. The CHAP has a section to be completed by the person, family and support worker to give the doctor information about the person's health situation.

It is a promising start that 8,700 people have benefited from the new assessments in the first 18 months. But, that is only a small proportion of the population of people with intellectual disability. Hopefully, the take-up on the assessments will steadily grow as word spreads about the practical benefits they are bringing.

Recent presentations, meetings and activities

November

Australasian Society for the Scientific (Study of Intellectual Disability (ASSID) in Melbourne - six presentations

Monash Bioethics Intensive on *Prenatal Diagnosis*

December

Psychiatric Registrars and Child and Youth Psychiatry Registrars

January

Queensland Office of the Public Advocate

Senator Shane Newman

Monica Cuskelly, Centre of Excellence in Behaviour Support, Ipswich

Senator Claire Moore

Kerry Rae, MP

February

L'Arche on Health of People with Intellectual Disability

Combined Catholic Pastoral Councils Meeting, Sydney

Medical Education Program, UQ

March

DSAQ Medical Issues Sub-Committee Centre of Excellence in Behaviour Support, Ipswich

QUT Human Services, Disability Studies Department of Human Services, Victoria Australian Divisions of General Practice National Caucus on Social Policy Intensive Behavioural Support Teams, DSQ

Fragile X Syndrome

The Fragile X Association of Australia in conjunction with QCIDD hosted a free one-day seminar in late 2008 on Fragile X Syndrome for more than 100 family members, health



professionals and educators.



Dr Jonathon Cohen (Medical Director Fragile X Alliance Clinic) with Associate Professor Nick Lennox (Director, QCIDD)

A small number of families affected by Fragile X are keen to set up a Queensland based sup-port network. Interested individuals or families who may wish to participate in planning this sup-port group or network should contact Mel Mikkelsen, Fragile X Association,

mikkelsen family@optusnet.com.au

Staff Profile

Dr Madonna Tucker— Behavioural Support Consultant

Dr Madonna Tucker was nominated in late 2008 for the QUOVUS Eminio Award on Individual Excellence in Inter- Agency Networking and Case Coordination. This is no surprise given the amount of work Madonna does! She manages the Challenging Behaviour Mentoring Programme which provides educational resources and mentoring support to participants from Non-government agencies in regards to positive behavioural support. Over the past six months, she supervised a Masters of Educational Psychology intern. Madonna recently participated in a reference panel for the development of policies and procedures in light of the new Legislation for Disability Services Queensland on restrictive practices. Madonna maintains links with other behavioural support positions in Queensland and the current Intensive Behaviour Support Teams, Disability Services Queensland. Senior Psychologists and other members of the teams have attended the QCIDD's clinical meetings. Madonna takes weekly telephone/email consultations concerning clients with positive behaviour support issues.

Madonna as the President of ASSID Queensland (Australasian Society for the Scientific Study of Intellectual Disability) is keen to make the links between researchers and people working and living with intellectual disability. http://www.assid.org.au/

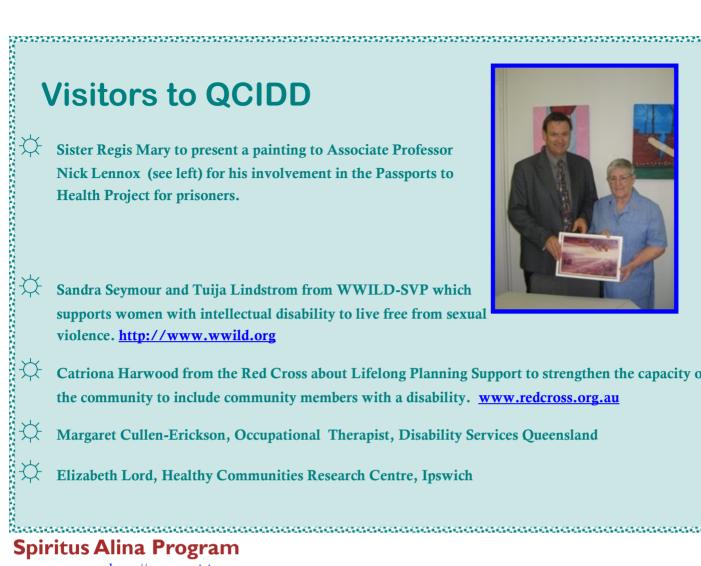
" Challenging Behaviour Mentoring Programme" - Update

Dr Madonna Tucker is the project manager of this programme. This programme is a response to the number of organisations struggling to respond to the needs of individuals with challenging behaviour. The programme invests in specific workers within non-government organisations to not only increase their knowledge base in positive behaviour support, but also to establish sustainable ongoing support networks to assist them in their roles. This programme has been extended for a further six months, with most participants electing to continue with the programme.

Participants are also linked to a skilled behavioural support practitioner for individual support and coaching. The participants communicate with their mentor through regular email conversations and a one hour phone consultation each month.

The mentoring model represents an investment in individual staff members and the organisations in which they work, in order to improve the outcomes for people being supported through those services. QCIDD believes that this programme is achieving those goals. This programme has been a very rewarding experience for all involved. The project has received very positive responses thus far.





Catriona Harwood from the Red Cross about Lifelong Planning Support to strengthen the capacity of

Spiritus Alina Program

http://www.spiritus.org.au

Service Profile

Working alongside people with an intellectual disability

In the late 1980's Alina was established as an initiative of the Anglican's Women's Hostel to address the need for single women with an intellectual disability who were homeless or at risk of homelessness and provide them with accommodation and support. Over the years this need evolved to encompass families as the women entered into relationships and started families. Today, Alina is a time-limited, inclusive, strength based program which works alongside people with an intellectual disability who live within a 30 minute drive from Nundah. There are two distinct groups which we seek to work alongside.

Families that are headed by a parent/parents who have an intellectual disability with a child under the age of 12 months. We work alongside the primary person who enters Alina of their own choice to engage in case management support within their family centred goals. This can include maximising independence, community participation, accessing other services, and parenting issues/challenges and successes.

Single women (18 and over) who have an intellectual disability and who are homeless or at risk of homelessness who enter Alina of their own choice to engage in case management support. This support is within the context of acquiring and maintaining stable accommodation. This can include accessing other services, maximising independence, and community participation.



Vol 1, Issue 2