



Located at
the Mater Hospital,
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August 2011

Vol 4, Issue 3

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.

QCIDD CLINIC UPDATE

Dear QCIDD supporters,

Hello, spring welcomes us to new things and new ideas.

Our waiting time for the clinic is about 8 weeks at the moment. However our clinic is still experiencing a high demand for service. There have been a few staff changes at QCIDD over the last couple of months.

These are exciting times for disability with the NDIS - National Disability Insurance Scheme recently being announced by the Federal government.

In this newsletter we have asked people to share their stories with us. I think it is important to share information with each other as the journey through life with a disabled child/ adult can often be a lonely one. So please share your stories with us.

If you have any queries about the QCIDD Clinic please phone us on (07) 3163 2524 or email jgibson2@uq.edu.au

In this issue:

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Are you a story teller??

Share a story on your child in our newsletter!

Tell a story about your child and how they are an inspiration to your family

Welcome to our new staff

QCIDD is fortunate to have talented new staff members.

Dr Margo Lane is our new GP and is also the driving force behind one of our new projects, the SHAP or Students as Health Advocates. This project involves medical students from the University of Queensland who spend time with service users from Endeavour Foundation and support them when they go for their annual Comprehensive Health Assessment Program or CHAP. Margo is also a course coordinator in the MBBS program at the UQ Ipswich Campus. Margo is also undertaking research around the SHAP by interviewing students who undertake the project.

We welcomed Julie Gibson to the role of Nurse Clinical Coordinator in July. Julie has a nursing background and brings a wealth of knowledge and experience to her new position, previously working with both Youngcare and the Mater Hospital's Complex Care Services. She has hit the ground running, and has already begun working in close consultation with our clinical team and service users, their parents and carers. Please see the new clinical information brochure to find out how to get in contact with Julie to discuss your referral to the QCIDD clinic on (07) 3163 2524 or email on jgibson2@uq.edu.au

As the third new member of the clinical team, we also welcomed Jenny Curtis in July this year. Jenny has joined QCIDD in the role of Clinical Administration Assistant, after discharging from the Australian Defence Force. Jenny is filling the shoes of our recently retired Ros Murrell. Jenny has brought a beautiful warmth and energy to the QCIDD office, and wowed us with her amazing computer skills! Over time we also hope to benefit from her interest in health and fitness. Jenny will be working closely with Julie Gibson, and Julie Joughin up in our clinic reception, to support our doctors and service users from the clinic.

Welcome to all, looking forward to great collaborations.

Farewell

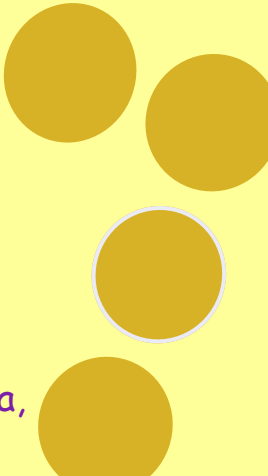
It is with sadness that we farewell Ros Murrell, our Research Support Admin Assistant, who has been with us for more than 10 years and who has now retired. We will miss her gentility and common sense, and we wish her well in her new life with her grandchildren.

Julianne Yates who worked on the Ask Project has also left us after four years and we will miss her great sense of humour and down-to-earth attitude.

Dr Robert Craig has now retired and we will miss him as will his patients. We would like to thank Robert for his contributions to the QCIDD clinic, Prader Willi clinic, Centre research, the clinic team and QCIDD as a whole. We wish Robert well in his new life.

We also farewelled Dr Madonna Tucker in August. Madonna, our Psychologist has been with QCIDD since 1998 with a couple of breaks adding to her family. Madonna in her role as President of ASSID, convened the ASSID National Conference in 2010. We will miss her common sense, guiding force and Christmas cheer. Best wishes to Madonna and her family.

DID YOU KNOW??

- About 15% of the world's population lives with some form of disability, of whom 2-4% experience significant difficulties in functioning.
 - As of 1st July 2011 all phone calls to Life Line are **FREE!!**
 - **Call anytime 24hrs on 13 11 14**
 - QCIDD has made a contribution to the **FIRST** World Report on Disability! **GO TEAM !**
 - A clinical trial for Fragile X is being undertaken in Australia, **Are you interested in participating??**
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OUR LATEST COLLABORATIONS

Vol 4, Issue 3

- ASID
- QUT
- Endeavour Foundation
- Bachelor Oral Health
- QDN
- Uni Quest
- IDN WG (QLD Health)
- South West Brisbane Disability Network
- Relationship, Sexuality Disability Network
- Centre of excellence for behaviour support
- Ipswich City Council
- Brisbane City Council (Disability Action Plan)
- Growing Strong Forum
- Round table meeting with the Minister
- WWILD
- Open Minds
- Department of Communities SRS Team
- Health Commission QLD
- Prof. Sylvia Rodger
- BOLD
- UQ
- MMRI
- UQ Mater Centre for Primary Health Care Intervention
- AEIOU
- CRU
- Prof. Pat Neuwelt, Public Health University of Auckland
- Prof. Helen Leonard, University of WA
- Carers QLD
- Workforce Council
- Blue Skies
- Forensic Mental Health (QLD Health)

Websites for Information on:

Grants: <http://www.uq.edu.au/research/rid/grants-smart-futures-fellowships>

OR <http://www.uq.edu.au/research/rid/grants-rpp>

Sexuality: <http://sex.sagepub.com/> OR <http://sex.sagepub.com/content/14/4/479>

Autism: <http://aut.sagepub.com/>

OR <http://aut.sagepub.com/content/early/2011/07/27/1362361311412058>

World Health Report: http://www.who.int/disabilities/world_report/2011/en/index.html

Society for the Study of Behaviour Phenotypes: <http://www.ssbp.co.uk/ssbp/>

Fragile X Syndrome: www.fragilex.org.au

Disability Parking Permits: <http://disabilityparking.gov.au>

National Companion Card: <http://www.companioncard.gov.au>

Inspiring and Positive stories: www.365Grateful.com

Resources, Services, Information and Products for people & families with Disabilities: www.e-bility.com

Courses / Workshops / Conferences

Family Planning: http://www.fpq.com.au/event_cal.php

SSBP: www.ssbpconference.com

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|----|-----------|---|
| 16 | September | 60 th anniversary of Endeavour Birthday celebrations / Stories |
| 21 | October | Advocacy at all different levels from its simplicity to complex |
| 18 | November | Update on FaHCSIA's and Business Services, Fed Funded services |

Please direct all enquiries and mail to both or either of the Local Parent Group's Coordinators

Henk Horchner, 1 Waterbrook Crt Bracken Ridge 4017 Ph: 3261 5380, e-mail HenkDeniseHochner@bigpond.com

OR Kevin Guilfoyle, 51 Ashford Court Petrie 4502 Ph: 3285 5590, e-mail gfoyles3@bigpond.com

Family Planning Queensland

Communicating about sexuality with people with intellectual disabilities

These are full day workshops (9am-3pm) with strategies to assist service providers to learn more about communicating and teaching about sexuality, with ideas to use in their workplace.

13 October Lawnton, 27 October Brisbane, Creastmead 22 November

For more information contact Kerry Smith Ph: 3250 0240 Email: education@fpq.com.au

Queensland Health

Parent / Carer Skills Based Training for Eating Disorders

Understand more about eating disorders, Learn helpful communication skills, Develop positive coping strategies, Foster a healthier relationship with your loved one Lawrence House Windsor, 30th August, 6th, 13th, 20th, 27th, September, to register please contact Eating Disorders Association (EDA) on 3394 3661

NDIS

19th September (1230 -4.30) Lutwyche Centro Shopping Centre **RSVP:** michelle.ryan@nds.org.au by 15 September.

37th AMTA National Conference

17 and 18 September, Royal on the Park Hotel, corner of Alice and Albert Streets, Brisbane, visit www.austmta.org.au/conf/ for more information

21st Congress of the International Association for Disability and Oral Health

17 to 20 October 2012 Sydney, NSW, Australia. Keynote speakers: John D.B. Featherstone, Mark S. Wolff, DDS, PhD, Jaime A. Cury, Yasmi O. Crystal, DMD, Cesar A. Migliorati DDS, MS, PhD. contact Sandra Rae or visit www.iadh2012.com

Pragmatic Organisation Dynamic Display (PODD) Introductory Workshop

8th and 9th November 9.00am – 4.30pm Jindalee Hotel and Function Centre, Sinnamon Road, Jindalee QLD (on-site parking available)

Target Audience: special school/SEU/ECDP teachers, teacher aides, speech pathologists, SLP/teaching students, parents and other support staff, RSVP: 7th October (numbers will be limited – so hurry!) Enquiries to Melanie Waalder or Paula Hartwig, 0413 885 939, or email to agosciqldrep@hotmail.com



THE UNIVERSITY
OF QUEENSLAND
AUSTRALIA



cerebral palsy league

cptfld.org.au

Keeping People with Communication Disability Safe in Hospital

Do you have Cerebral palsy and Difficulty Talking?

Have you been to hospital in the past year?

Do you know an adult with cerebral palsy or aphasia who has been to
hospital in the past year?



- We would like to talk to you about your experiences in hospital.
- We are interested in any 'adverse events' that may have happened.
- We will ask you about what happened and the impact of this upon you.
- Your family member or carer can be with you when you talk to us.

If you would like to talk to us please contact Dr. Bronwyn Hemsley at The University of Queensland on (07) 3365 2089 or (0411) 730832 b.hemsley@uq.edu.au or contact your service provider to let them know your interest. Bronwyn will then send you an information sheet about the study.

**Experiences of Patient Safety Incidents in Adults with Communication Disability in
Hospital**

Ph: Bronwyn Hemsley on (07) 3365 2089

Email: b.hemsley@uq.edu.au

Version 1 15th November 2010

March to August 2011 Presentations

Prof Nick Lennox

Health & healthcare for people with intellectual disability, Office of the Adult Guardian, Brisbane

Heart Health QDN's men's interest network, Bowen Hills

Parent to Parent Day, Improving the health and well being for people with Intellectual Disabilities, Nambour

Love in the time of Randomised Controlled Trials—using what we know to make a difference, Leadership, Change & Best Practice in Disability Support, Gold Coast

Annual Health Review for people with an Intellectual Disability, a Master Class: Division of General Practice Victoria

Prof Nick Lennox & Dr Cathy Franklin

Adults with intellectual disability, Mental Disorder-context assessment and management, Psychiatry Registrars year 3

Dr Gillian Eastgate

Living with disability, Medical students 1st year, UQ Brisbane & Ipswich

Sexuality, sexual abuse and Protection Skills: a Study of Family Members and Support Workers, ASID national conference 2011,

Workplace attitudes to sexuality, relationships and disability, Relationships and Sexuality Disability Network, Mater Hospital

Dr Madonna Tucker

SRS Team Disability Services, Wacol

Miriam Taylor

Communication with people with intellectual disability, MBBS Students as health advocates, Ipswich

Intimacy and sexuality, Family Networks Workshop, Nambour

Disability Social Work and Therapies, Year 3, UQ St Lucia

Adults with intellectual disability, Working with disadvantaged populations, Brisbane

Miriam Taylor & Peter McMeekin

Working with Disadvantaged Patients, People with intellectual disability and social health determinants, UQCCR

Miriam Taylor & Rod Mills

Communication with people with disability in emergency situations, Ambulance Services Qld State Training, State wide

Miriam Taylor & Sabrina Stokes

Communicating with parents with intellectual disability, Parents with intellectual disability, State Library

Miriam Taylor, Claire Mitchell & Rod Mills

Beating the Barriers: Oral Health, Issues for Adults with Intellectual Disability, Dental school, Year 3 Students UQ

Shannon Dias

Physical health outcomes in prisoners with Intellectual Disability: a cross-sectional study, ASID state conference 2011, UQ Ipswich

Clinical Trial in Adults with Fragile X

Hunter Genetics in Newcastle and the NSW Developmental Disability Health Unit in Sydney are participating in a clinical trial testing a new treatment for Fragile X syndrome. The treatment is a capsule and the medication is taken twice daily for 12 weeks.

To be eligible to participate in the trial, patients must fit the following criteria:

- Be aged 18-45 in otherwise good general health. If female, you must be willing to use contraception for the duration of the study.
 - Have a previous diagnosis of Fragile X based on genetic testing (full mutation)
 - Have a caregiver who spends on average at least 6 hours a day with the study participant and is willing to supervise treatment, attend all study visits and assist with study assessments
- Have a documented mild to moderate intellectual disability (IQ score less than 70)

The study lasts for a total of approximately 21 weeks and includes a 4-week screening period, up to 16 weeks' treatment and one week follow up

If you would like more details on the trial, please contact Carolyn Rogers or Jackie Boyle at Hunter Genetics on (02) 49853136 or (02) 49853100.

Professor Lennox is a researcher, educator, advocate and clinician. He has specialised in the health of adults with intellectual disability since 1992 after training in general practice and for a time in psychiatry. Professor Lennox has been instrumental in development of the Management Guideline Developmental Disability, Therapeutic Guidelines Book and part of the WHO World Report on Disability & Rehabilitation. He developed the Comprehensive Health Assessment Program (CHAP) which is used throughout Australia and overseas and successfully advocated for a Medicare payment to enable GPs to perform annual assessments. Professor Lennox was a panellist on the Mental Health and Intellectual Disability webinar.

BOOKS OF INTEREST

Sonia's Feeling Sad - by Sheila Hollins and Roger Banks

Sonia, a young woman with learning/intellectual disabilities, is very sad and avoids seeing her family and friends. At home, she cries a lot and prefers to be in bed – although she can't sleep. Sonia's GP says that she is depressed and suggests that she see a counsellor. Regular visits to the counsellor - over the course of a year - help Sonia to feel better, and she starts to enjoy life again. (July 2011, 56 pages, ISBN 9781908020093, £10)

Buy online at: <http://www.rcpsych.ac.uk/publications/booksbeyondwords/bbw/9781908020093.aspx>

Ron's Feeling Blue (2nd edn) - by Sheila Hollins, Roger Banks and Jenny Curran

Ron has lost interest in the things he usually enjoys; he doesn't want to see his friends or take part in any activities. He stays in bed and gets angry when his friends try to talk to him and bring him food. His GP visits and diagnoses Ron with depression. Ron sees his GP regularly who helps him to feel better – he starts to enjoy doing things again. Two additional images illustrate the doctor prescribing medication for the depression. (July 2011, 54 pages, ISBN 9781908020086, £10)

Buy online at: <http://www.rcpsych.ac.uk/publications/booksbeyondwords/bbw/9781908020086.aspx>

Loving Each Other Safely - by Helen Bailey and Jason Upton

This book explains what you need to do to stay healthy and safe in a loving sexual relationship. Ed is jealous of other couples and wishes he had a girlfriend. He fancies Lauren but initially doesn't understand how to manage his feelings. Ed's brother gives him some advice. Ed and Lauren have a successful first date and grow to like each other a lot. How can they love safely though? Advice is given about starting a relationship and knowing when you are ready for sex. There is also information on consent, masturbation, contraception, sexually transmitted infections (STIs) and what to expect at a sexual health clinic. (July 2011, 66 pages, ISBN 9781908020291, £10)

Buy online at: <http://www.rcpsych.ac.uk/publications/booksbeyondwords/bbw/9781908020291.aspx>



QCIDD's part in the very first World Disability Report

QCIDD's contribution to the first World Report on Disability was Chapter 3! We are feeling proud of the big effort and we know that our efforts will impact on Australian policy on disability and on the lives of people with disability in the future.

More than one billion people worldwide experience some form of disability, the United Nations and the World Bank said today in a report that calls for the elimination of barriers that often force the people with disabilities to "the margins of society."

The [World Report on Disability](#), developed by the World Health Organization ([WHO](#)) and the World Bank, with contributions from over 380 experts, urges governments "to step up efforts to enable access to mainstream services and to invest in specialized programs to unlock the vast potential of people with disabilities."

"Disability is part of the human condition," said WHO Director-General Margaret Chan at a ceremony in UN headquarters to launch the report. "Almost every one of us will be permanently or temporarily disabled at some point in life."

"We must do more to break the barriers which segregate people with disabilities, in many cases forcing them to the margins of society," Dr. Chan said.

Etienne Krug, a WHO disability specialist, suggested that the barriers themselves are a cause of disability. "Disability results a lot from the barriers that society erects for people with disabilities," he said, "barriers such as stigma and discrimination; such as lack of access to health services and rehabilitation services or problems of access to transportation and buildings and information services."

About 15% of the world's population lives with some form of disability, of whom 2-4% experience significant difficulties in functioning. The global disability prevalence is higher than previous WHO estimates, which date from the 1970s and suggested a figure of around 10%. This global estimate for disability is on the rise due to population ageing and the rapid spread of chronic diseases, as well as improvements in the methodologies used to measure disability.

More information: http://www.who.int/disabilities/world_report/2011/en/index.html



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.

Sponsorship

AADDM 2012 encourages organisations to become a sponsor of the conference, which will be recognised in the Conference Website and Brochure as follows:

Sponsorship Value \$10,000 or more: **Platinum Sponsor**

Sponsorship Value \$5,000-\$9,999: **Gold Sponsor**

Sponsorship Value \$1,000-\$4,999: **Silver Sponsor**

Display

We encourage you to consider whether your organisation may wish to display information of relevance to AADDM 2012 Conference delegates. Organisations must provide all equipment and furniture for their displays.

Whilst there are no specific fees levied for display, we have the following requirements for organisations wishing to display:

For the not-for-profit and consumer/carers sector:

- ☐ Payment of the registration fee for each individual manning the display.
- ☐ Payment of bursary equivalent to a minimum of two full standard registrations at the carer/consumer rate.

Other organisations:

- ☐ Payment of the registration fee for each individual manning the display.
- ☐ Payment of bursary equivalent to a minimum of two full standard registrations at the student rate.

Organisations will be recognised as sponsors of the bursaries for consumers/carers and students in the Conference brochure.