

Located at
the Mater Hospital,
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Place
South Brisbane
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qcidd@uq.edu.au



April-June 2016

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

A message from the Director

Over the last few months we have had at least three reasons to celebrate. Firstly we have just released the ASK diary as an iPhone and iPad App and the Able X series on people with intellectual disability and health, these are now up and running with thousands of participants across the globe. Finally our extra ordinary education coordinator won the 2016 UQ award for excellence in Equity and Diversity (Individual category)! Congratulations Miriam.



At this time I think it is timely to reflect on what QCIDD has achieved over the years. For me there have been many contributions made to improve the health and healthcare of people with intellectual disability.

At the core has been excellence in what QCIDD staff try to do be it clinical practice, research, teaching or advocacy.

I think we can hold up our heads and be proud of what the centre has achieved and expect these innovations and ongoing good work to continue.

I want to acknowledge the ongoing aspiration to excellence in the delivery of health and mental health services. It is a service that respects, listens to and proactively seek to address the deficits in health and health care. This connectedness to the health care service reality has always driven and inspired me to think what we can do to improve the dreadful health, health care and "devaluing" situation endured by people with intellectual disability. This is difficult, time consuming and complex work – indeed as Prof Keith McVilly noted in his MOOC interview this work "IS Rocket Science". It is a tough gig for the clinicians – uncertainty, lack of accessible care pathways, profound exclusion of this population from reasonable decision making processes in health and elsewhere.

For me through this connection with people with intellectual disability in clinical practice has helped create/drive the many QCIDD world firsts and other innovations. The QCIDD staff and supporters have all contributed to many of these innovations over the years.

These include

- Therapeutic guidelines series the first whole of life book on developmental disability medicine
- RCT Evidence of CHAP health check improving healthcare delivery which drove the subsequent change in health policy, Medicare and medical practice in Australia/NZ and UK
- Ask diary evidence of improved health advocacy & empowering people
- The invitation to write the intervention chapter in UN World Report on Disability 2011
- Our brilliant accessible website and those accessible resources <u>www.qcidd.com.au</u>
- On line RACGP and support worker training programs
- Able X series & the future inclusion of these courses in various family, disability and health training programs across the globe
- Ask Health diary App released on Wednesday 08/06/2016
- Adult Autism interventions currently being developed such as Cindy Nicollet's Acceptance & Commitment Therapy for people with autism and anxiety, and the other Autism health hub materials.

Well done team!! And thankyou to you our supporters as none of this would have occurred without the input of people with intellectual disability, their families and supporters. Finally I would like to acknowledge Queensland Health and Disability Services who have funded the core activities of the centre and the fantastic support of the Mater Hospital and more recently Mater Research Institute under stewardship of Prof John Prins.

Nich Lennox



Miriam Taylor, Prof Nick Lennox Alastair Smith (ASK App developer) https://appsto.re/au/pkVubb.i

QCIDD Education

Since March 2016, the QCIDD educators have done a great deal of work!

Prof Nick Lennox has been very busy presenting to a range of audiences here in Australia, and most notably in Canada and the USA – at the <u>Canadian Conference on Developmental Disabilities and Autism 2016</u> and the <u>International Society for Autism Research Conference</u> in Baltimore. His presentation to the Research in Progress Meeting, Oregon Science and Health University USA, was entitled "Improving the health & wellbeing of adults with Autism: Big ideas with a small budget". On his return, Nick presented to the <u>Metro North Health Forum</u> on "The invisible people - En-Able better primary healthcare for people with intellectual disability".

For the twelfth year running, Peter McMeekin has co-presented to The University of Queensland students, and recently to Dentistry, Medical and Therapy students in separate lectures with Anna Urbanowicz and Miriam Taylor.

Meanwhile, Miriam has been co-presenting with long-time tutor, Rodney Mills, on Health Policy in Practice to UQ Public Health students, on disadvantaged patients to the GP Rotation in Medicine, and on disability, sexuality and health for Medical students. Miriam was an invited guest for the **Zero Tolerance Panel** at the **National Disability Services Conference**.

Cindy Nicollet co-presented to second year Psychology students at UQ with long-time tutors, Claire and Julie Mitchell, and Dr Cathy Franklin presented a case study to the **MYAHCB Grand Rounds**.

Dr Gillian Eastgate presented to the <u>Multicap Client Outcome Committee</u> on "How to prepare for attending a general practice consultation with a client".

So on top of all the <u>Able X Series</u> work, the team has been very busy and the year is barely half-way through!

We will continue providing high quality educational activities and presentations, as we work to embed the **ABLE XSeries** in university courses around Australia.

Miriam Taylor
Education Coordinator



Miriam Taylor being presented the UQ Excellence Individual Award for Equity and Diversity by the University of Queensland Vice-Chancellor, Professor Peter Høj, at a formal ceremony on 9 June 2016

https://www.hr.uq.edu.au/recognition/uq-awardsexcellence-2016-recipients

QCIDD CLINIC

The QCIDD clinic is located on Level 4, Salmon Building (off Stanley Street) in the MYAHCB – Mater Young Adult Health Centre Brisbane. The consultation rooms are bright and roomy with the waiting room having sufficient space for wheelchairs and accommodate a greater number of patients, families and carers.

We are very excited to welcome Dr Matthew Cadman to our QCIDD clinical team. Dr Cadman is a General Practitioner working on Wednesdays with clinic in the mornings. He brings with him a wealth of experience and we look forward to working with Dr Cadman.





We are also very pleased to announce that Dr Oreste Theodoratos, Consultant Psychiatrist will be staying on in the clinic until mid-September. Dr Theodoratos will be at clinic on Wednesdays.

If an appointment needs to be confirmed with the clinic staff the phone contact is (07) 3163 5800.

If you are wishing to re-arrange an appointment please contact QCIDD on (07) 3163 2412.

QCIDD CLINIC UPDATE

The current waiting list times:

- Prof Lennox (Director, General Practitioner)—12 months
- Dr Cathy Franklin (Consultant Psychiatrist)—6 months
- Dr Gillian Eastgate (General Practitioner)—6 months
- Dr Matthew Cadman (General Practitioner)—1 month
- Dr Oreste Theodoratos (Consultant Psychiatrist)—2 months
- Cindy Nicollet (Psychologist)

If you have any queries about the QCIDD Clinic please contact Julie Gibson: phone (07) 3163 2524 or email j.gibson2@uq.edu.au.

Julie Gibson Clinical Coordinator

Telepsychiatry Clinic (Skype Consultation)



QCIDD continues to run its telepsychiatry clinic fortnightly on a Tuesday morning.

Updated information

- Q: What is a Telepsychiatry clinic?
- A: This is a clinic using the internet and a videoconferencing programme (e.g. Skype or via Qld Health videoconferencing) to talk with people. The Psychiatrist (Dr Franklin) consults with the patient, their family and / or carers over the internet. This could be from the person's home (using Skype on a personal computer) or from a Qld Health Hospital using the Hospital's videoconferencing facilities.
- Q: Who can access the service?
- A: Referrals can come through the existing referral pathway for QCIDD. The usual eligibility criteria for QCIDD apply (patient is age 17 or over and has an intellectual or developmental disability).

If you are interested in telepsychiatry and you have the equipment (see below) and live in an eligible area (see below) we can proceed to book the patient for a consultation.

- Q: What equipment do I/we need?
- A: You need access to a computer that has a camera and sound, and can access the internet. At present we are using Skype, which means you may have to install Skype on your computer. By next year we aim to be using a simpler system that you can just click a link to access.
- Q: What if I/we don't have access to a computer?
- A: Some people prefer to do this at their GP's surgery. Some GP surgeries (especially in rural and remote regions) have the necessary technology and are happy to do this.

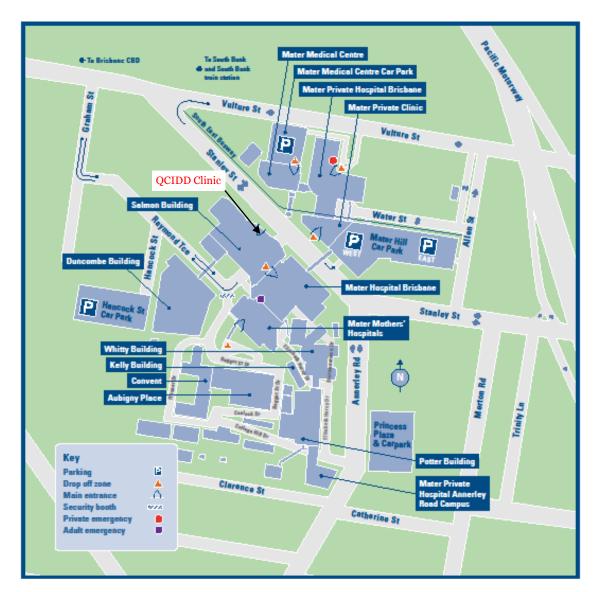
In other cases there may be a care organization involved in paid care for the patient who may have access to a suitable computer.

Alternatively, many regional and rural Queensland Health hospitals already have videoconference facilities that can be booked.

- Q: What is an eligible area?
- A: People who live in Brisbane or parts of the Gold or Sunshine Coast are not eligible for this service currently. If unsure, please ask us and we will find out for you.
- Q: What is the cost?
- A: This service is free to the patient and is supported by the Mater Hospital.

Our experience so far is that whilst this service does not replace our face to face clinic, it has been of great help to people outside of Brisbane who cannot otherwise access specialised mental health care for people with an intellectual or developmental disability.

QCIDD Clinic



Mater Health Services

Mater Hill, South Brisbane campus map

QCIDD Clinic L

Level 4, Salmon Building

Stanley Street

South Brisbane QLD 4101

The clinic is situated on level 4 of the Salmon Building, and is part of the Mater Young Adult Health Centre Brisbane (MYAHCB). Entry: take the lift on the ground floor on Stanley Street to level 4, turn left and proceed to the reception area.

Parking: there is a disabled car park on Stanley Street or park in the Mater Hill (Water Street) Car Park.

Alternatively you may park on the street in a metered space.

PLEASE NOTE: if you have specific mobility issues,

please contact the Clinical Coordinator on (07) 3163 2524 for advice/assistance.

This should be done well in advance of the appointment.

QCIDD Research

Tan Doan

In 2010 a young Vietnamese pharmacy graduate named Tan Doan came to Brisbane to study for his Masters in Health Economics at The University of Queensland. During his studies Tan applied for a summer scholarship at QCIDD where his task was to analyse data collected as part of our CHAP studies. Although he worked on several projects, it was in using his pharmacy qualifications that he was able to make the greatest contribution producing an article on medication use by adults with intellectual disability. As lead author he took control of the submission process, re-writing and re-submitting the paper until it was accepted and published. Tan's initiative, intelligence and good nature encouraged us to offer him a second scholarship in 2011, where he produced an excellent research paper on medication use in adolescents with intellectual disability. Both papers have been cited many times since publication which is evidence of the quality of his work.



Tan Doan
PhD graduation May 2016

On leaving us in March 2012, Tan went to Melbourne to begin his PhD at Monash University in pharmacy and mathematical modelling. After successfully submitting his thesis last September, Tan took up a position as Research Fellow in the Department of Medicine and Radiology at the University of Melbourne. His research interests span from transmission dynamic modelling of infectious diseases, particularly tuberculosis and hospital -acquired infections, to health economics, global health, pharmacokinetics-pharmacodynamics and pharmacy practice. It was his interest in infectious disease which prompted his recent move to the Australian Institute of Tropical Health & Medicine to work with one of his PhD Supervisors in Townsville at James Cook University.

As Tan's brother lives in Brisbane, in recent years we have been able to catch up when he has been visiting. We were able to share with Tan his excitement at the birth of his first nephew when he came to meet him after his arrival last September. More recently in April we were also able to share Tan's wedding celebrations. His beautiful bride Theresa is a Brisbane girl which should mean we will be able to keep seeing him from time to time.

On looking back through my emails to confirm dates, I came across this one titled "PhD finished and employed" and was very proud to read again what he had written: "My time at QCIDD helped me discover my passion for medical research, and the skills and experience I gained while working with you all helped me tremendously in getting my PhD scholarships and during my PhD journey".

Lyn McPherson Research Coordinator



Tan and Theresa Doan



Theresa and Tan Doan Lyn McPherson, Dell Hele, Dr Robert Ware

Autism CRC

QCIDD contributes to Program 3 of the Autism CRC that aims to improve opportunities for people living with autism to successfully transition to post school life, participate in higher education and employment, and identify best practice in health management.



Please read on to find out more about our exciting projects and how you can get involved. You do not need to have a diagnosis of autism to participate in a number of these projects. We would like to thank everyone who has already participated for their valued contribution.

Anxiety Program for Adults

We are looking for adults on the spectrum to participate in an anxiety program. The program is based on Acceptance and Commitment Therapy (ACT), which focuses on the pursuit to living a valued life. Eligibility to participate in the anxiety program will be determined by meeting diagnosis of autism, an anxiety disorder, and an IQ of 80 or above. The program will be delivered in Brisbane, QLD.

Please contact Ms Cindy Nicollet on (07) 3163 2496 or c.nicollet@uq.edu.au to find out how to participate.

Comprehensive Health Assessment Program (CHAP) for Adults

We have adapted the Comprehensive Health Assessment Program (CHAP) for adults on the autism spectrum with intellectual disability and are currently undertaking an evaluation of the adapted CHAP. The evaluation involves the adult visiting their GP to complete the adapted CHAP. This project is being carried out in Brisbane QLD, Melbourne VIC, Sydney NSW and Perth WA.

If you are interested in participating in this project please contact Ms Anna Urbanowicz on (07) 3163 1983 or autism.adulthealth@uq.edu.au .

Australian Longitudinal Study of Adults with Autism (ALSAA)

Researchers from the Autism CRC and the University of NSW are looking for adults to participate in a nation-wide questionnaire based research study which aims to improve our understanding of the health and wellbeing of autistic adults and their carers in Australia. To be eligible, you must be:

- i) an autistic adult over the age of 25 and living in Australia, OR
- ii) a non-autistic adult over the age of 25 and living in Australia, OR
- iii) a carer or family member of an autistic adult over the age of 25

We are in urgent need of non-autistic adults to fill out the questionnaire so if you're willing to help or know someone who might be, please contact Dr Kitty Foley or Ms Jane Hwang on (02) 9385 0620 or autismcrc@unsw.edu.au or go to this link:

https://autismcrc.au1.qualtrics.com/jfe/form/SV_1UoHxIKX4M0WRo1

School Leavers Longitudinal Study

Researchers from the Autism CRC and the Olga Tennison Autism Research Centre are looking for young adults on the spectrum aged 15-24 years, their parents and young adults from the general population to participate in a nation-wide questionnaire-based study about understanding the process of transitioning from secondary school to either higher education or vocational training/employment for student on the spectrum and their families.

For more information please contact Dr Mirko Uljarevic (M.Uljarevic@latrobe.edu.au) or Ms Ru Ying Cai (R.Cai@latrobe.edu.au).

Want to find out how to regulate your emotions?

Emotion regulation has been shown to be associated with a range of positive and negative outcomes, such as academic, employment, social, and psychopathology.

Researchers from the Autism CRC and the Olga Tennison Autism Research Centre are inviting people 18 years and over to participate (individual with or without autism) in a study that will involve completing a 5-day emotion regulation diary using a mobile application to capture your emotions and how you regulated your emotions.

The aims of the study are to understand the types of strategies used by adults with autism, and explore the relationship between emotion regulation and outcomes (anxiety and depression) in adults with and without autism.

For more information please contact Ms Ru Ying Cai (R.Cai@latrobe.edu.au).

QCIDD links to view at your leisure QCIDD's website—https://www.som.uq.edu.au/research/research-centres/queensland-centre-forintellectual-and-developmental-disability.aspx QCIDD's person-centred website—www.gcidd.com.au ASK Diary (Advocacy Skills Kit Diary) https://itunes.apple.com/au/app/ask-diary-advocacy-skills/ id1095955087?mt=8 ABLE101x Through my Eyes—Intellectual Disability Healthcare around the World— https://www.edx.org/course/through-eyes-intellectual-disability-uqx-able101x ABLE201x Well and Able—Improving the Physical Health of People with Intellectual Disability— https://www.edx.org/course/well-able-improving-physical-health-uqx-able201x ABLE301x Able-Minded—Mental Health and People with Intellectual Disability https://www.edx.org/course/able-minded-mental-health-people-ugx-able301x QCIDD's YouTube channel— https://www.youtube.com/channel/UChCUpCHdvnHqAf8SBOuV tA Free online course for support workers about being a great health advocate for people with disability— http://www.ndsqldprojects.net/good-health-and-wellbeing.html Are you a doctor? Interested in boosting your points? Our free online 12-module course RACGP ALM Healthcare for People with Intellectual Disability is a further addition to the RACGP Curriculum on developmental disabilities and includes lectures, downloadable case histories, webinars, videos and links to external sites with addition information. Email to m.taylor3@uq.edu.au to receive an invite today. Do you have diabetes or do you support someone who does? If so, our free online printable manual, Diabetes to the Point, is available for you here—http://goo.gl/MSvfoo Scared of going for blood tests or CT scans or X-rays? Desensitise yourself here http://goo.gl/WmnUHg Having a yearly health check keeps you well, and here's why http://eshop.uniquest.com.au/chap/ Tweet to @QCIDD for up to-date news and ideas Facebook—https://www.facebook.com/gcidd.ug Other links of interest Upholding the right to life and health: A review of the deaths in care of people with disability in Queensland—A systemic advocacy report—http://www.justice.gld.gov.au/ data/assets/ pdf file/0008/460088/final-systemic-advocacy-report-deaths-in-care-of-people-with-disability-in-Queensland-February-2016.pdf Disability and a Good Life: Thinking through Disability https://www.futurelearn.com/courses/thinking-through-disability Disability and a Good Life: Working through Disability https://www.futurelearn.com/courses/thinking-through-disability Australian Association of Developmental Disability Medicine (AADDM)—http://aaddm.com.au/