



Located at  
the Mater Hospital,  
Level 2, Aubigny  
Place  
South Brisbane  
61- 07-3163 2412  
[qcidd@uq.edu.au](mailto:qcidd@uq.edu.au)



THE UNIVERSITY  
OF QUEENSLAND

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**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 Acting Director

QCIDD celebrates 20 years of success this year, since establishment as The Developmental Disability Unit in 1997. The centre has many successes to its credit in research, teaching, advocacy, and clinical service. Our long serving and eminent director, Professor Nick Lennox, is enjoying a period of well-deserved long service leave and reconnecting with Tasmania and his garden. In his absence, I am keeping the seat warm, having returned to QCIDD after about ten years away (and elsewhere in this newsletter I'll include a short piece to introduce, or reintroduce, myself).



In research QCIDD has a record of success, particularly in translational and clinically focussed research. Grant funding has led to important findings for health promotion and clinical care of adults with intellectual and developmental disabilities. QCIDD's involvement with the Autism Cooperative Research Centre (CRC) has brought opportunities for collaboration and important initiatives via the CRC include an autism specific CHAP and the "Health Pathways" project in collaboration with the Far North Queensland Public Health Network. As well as providing guidance for general practitioners caring for people with autism this project will provide opportunities for collaboration and data collection with and via the Network. Dr Anna Urbanowicz, employed as a post-doctoral researcher on the CRC, continues her excellent work in managing the various projects. Congratulations to Anna, also, for the award of her PhD for research on Rett's syndrome, since the December newsletter.

Since my appointment in January I've been exploring opportunities for collaborations in research. I hope to build on my earlier work at QCIDD on the use of antipsychotic medication, perhaps extending this towards translational research on cessation and rationalisation of medications among our patients. Other potential research activities include dental health research with Professor Pauline Ford, Dr Kelsey Pateman and others, lead and cognitive function with Dr Luke Knibbs, fetal alcohol spectrum disorder in remote WA (via ongoing PhD supervision at The Australian National University), and neonatal research.

We are still celebrating the successful launch of the Able-X MOOC in 2016, and again I congratulate Miriam Taylor and all other QCIDD staff involved in this activity. QCIDD contributes to the University of Queensland MD program and Dr Matthew Cadman has delivered two excellent lectures to the students within the last month.

*Dave Harley*

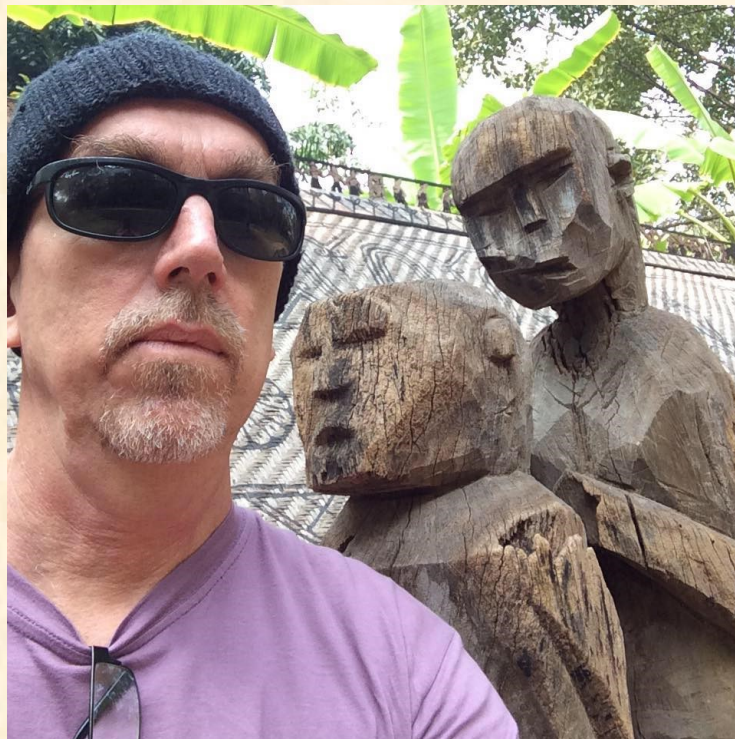
## **Associate Professor David Harley**

I commenced back at QCIDD, having worked here from 2002 to 2007, on 23 January this year. And so, I felt I should introduce myself, or for some reintroduce myself, to recipients of this newsletter.

Other than the period 2008 – 2016 and a few brief periods overseas, I've lived all my life in Queensland. I studied medicine at the University of Queensland and, in the early 1990s, left Brisbane for Far North Queensland. As well as the birth of my two daughters and work in hospital and general practice I completed my PhD in tropical health and my specialist training in public health medicine in Cairns. On my return to Brisbane in 2001 I worked in general practice, travel medicine, and at QCIDD for about six years. I then moved to The Australian National University (ANU) Medical School as Associate Professor of Epidemiology and chair of population health theme in the medical curriculum.

While I was primarily involved in clinical work while at QCIDD previously I also became interested in the prescribing of psychotropic, particularly antipsychotic medications, to my patients. So, I completed research as part of a multi-centre trial on the use of antipsychotic medications for aggressive challenging behaviour, showing no benefit over placebo (Tyrer et al., Lancet, 2008). I hope to continue research on prescribing of psychotropic drugs now that I've returned to QCIDD as Research Director.

As a practicing doctor, epidemiologist and public health physician my interests are broad. A major focus of my research over decades has been on infectious diseases, so should the opportunities arise I'm certainly enthusiastic about exploring links with intellectual disability, both as cause and consequence. I continue to supervise ANU PhD students, and three of these are completing projects of relevance to QCIDD: Tam Tran on road traffic injury in Vietnam; Latif Mohamed on benchmarking of neonatal intensive care units in NSW and the ACT; and Pip Dossetor on fetal alcohol spectrum disorder in the remote Far North of Western Australia. As alluded to earlier in the newsletter, I'm exploring collaborations in dental health and lead exposure.





# 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 has sufficient space for wheelchairs and can accommodate a large number of patients, families and carers.

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**.

In January we welcomed **Dr David Harley** to QCIDD. Dr Harley is Deputy Director at QCIDD and Acting Director while Professor Nick Lennox is taking long service leave.

We also welcomed back **Dr Matthew Cadman** to QCIDD after having some leave. With both these clinicians on board we hope to reduce our waiting time for appointments.

Patients should be notified about upcoming appointments via letter from Mater Health Services. Please let us know if this has not happened for your appointment as we endeavour to stream line the appointment process.

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# QCIDD CLINIC UPDATE

The current waiting list times are:

- Prof Nick Lennox (Director, General Practitioner)—12 months
- Assoc. Prof David Harley (Deputy Director, General Practitioner)—2 months
- Dr Cathy Franklin (Consultant Psychiatrist)—6 months
- Dr Gillian Eastgate (General Practitioner)—6 months
- Dr Matthew Cadman (General Practitioner)—1 month
- Dr Matthew Sellen (Psychiatry Registrar)—2 months
- Cindy Nicollet (Psychologist)—3 months

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

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 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 so 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**      **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.





## Autism CRC

QCIDD contributes to Program 3 of the Autism CRC that aims to improve opportunities for autistic individuals 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.



This year we have two honours students working on Autism CRC projects:

### **1. Comparing the dental health experiences and oral health needs of autistic adults and the general population.**

Prem Brahmhatt is a Bachelor of Health Sciences Honours student researching how oral and dental health experiences differ between autistic adults and adults from the general population. His research will require participants to complete an online survey about their oral and dental health needs and experiences. This project will provide important data to inform the delivery of oral and dental health services to autistic adults. Recruitment of participants will be commencing soon; if you are interested in participating please contact Prem at [premkumar.brahmbhatt@uq.net.au](mailto:premkumar.brahmbhatt@uq.net.au) or his supervisor Dr Anna Urbanowicz at [a.urbanowicz@uq.edu.au](mailto:a.urbanowicz@uq.edu.au) or (07) 3163 1983. Prem hopes to join the Doctor of Medicine program at the University of Queensland in 2018.

### **2. Developing a National Guideline for Autism Spectrum Disorder diagnosis in Australia – Examining the perspective of adults who have been diagnosed with ASD.**

Matthew de Broize returned to Australia three years ago to begin his university studies, prior to which he spent 16 years living in Asia. He is a Bachelor of Health Sciences Honours student researching the experiences of adults who pursue an Autism Spectrum Disorder diagnosis. Matthew's study is part of a broader project aiming to develop the first national guideline for Autism diagnosis in Australia.

Matthew is currently recruiting adults who identify as autistic to participate in an interview about their experience of seeking an autism diagnosis as an adult. Australian adults who fulfil one of the following criteria are eligible to participate:

- Individuals on the autism spectrum who received an autism diagnosis during adulthood, or
- Individuals who are currently involved in the autism diagnostic process, or
- Individuals who identify as autistic, but have not received a formal diagnosis.

If you are interested in participating please contact

Matthew at [matthew.debroize@uq.net.au](mailto:matthew.debroize@uq.net.au) or his supervisor Dr Anna Urbanowicz at [a.urbanowicz@uq.edu.au](mailto:a.urbanowicz@uq.edu.au) or (07) 3163 1983.

Following the completion of his honours project, Matthew wishes to transition into studying medicine.



Premkumar Brahmhatt, Anna Urbanowicz, Matthew de Broize

## Comprehensive Health Assessment Program (CHAP) for Adults

We have adapted the Comprehensive Health Assessment Program (CHAP) for autistic adults 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 Dr Anna Urbanowicz on (07) 3163 1983 or [a.urbanowicz@uq.edu.au](mailto:a.urbanowicz@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 study which aims to improve our understanding of the health and wellbeing of autistic adults and their carers. 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 Ms Jane Hwang or Dr Samuel Arnold at [autismcrc@unsw.edu.au](mailto:autismcrc@unsw.edu.au) or go to this link:

[https://autismcrc.au1.qualtrics.com/jfe/form/SV\\_1UoHxIKX4MoWRo1](https://autismcrc.au1.qualtrics.com/jfe/form/SV_1UoHxIKX4MoWRo1)

## School Leavers Longitudinal Study

Researchers from the Autism CRC and the Olga Tennison Autism Research Centre at La Trobe University are looking for young autistic adults 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](mailto:M.Uljarevic@latrobe.edu.au)) or Ms Ru Ying Cai ([R.Cai@latrobe.edu.au](mailto:R.Cai@latrobe.edu.au))

## SUMMER SCHOLAR

*The UQ Summer Research Program* provides an opportunity for students to gain research experience working alongside academics and researchers. By participating at QCIDD, it is hoped that students will extend their knowledge of the field of intellectual disability and develop their analytical, critical thinking, and communication skills, and at the same time enhance the research output of the Centre. QCIDD has had a number of Summer Scholars join us in recent years and several have gone on to publish the results of their projects in respected academic journals.



Over the 2016/17 summer vacation period, Canadian third year medical student Michael Wu worked with Prof Rob Ware and Lyn McPherson on a systematic review of the literature on “Interventions to improve influenza vaccination rates among high risk groups”. Influenza is a vaccine preventable cause of morbidity and mortality. Australian guidelines recommend routine vaccinations for all people aged greater than 6 months, and particularly for adults aged >65 years, pregnant women, people with Down syndrome, people with chronic disease, and people who are immunocompromised. People with intellectual disability in shared accommodation are particularly vulnerable to influenza, so it is important for us to be aware of strategies to increase immunisation rates that may have been successful with other similarly disadvantaged groups. Michael has done much of the hard work on this project over summer and hopes to continue to publish the work. This review will inform future research at QCIDD.

Lyn McPherson  
Research Coordinator



## QCIDD Education

### The ABLE X Series

In the first round of this popular massive open online course (mooc), we had 7000 students. Now in the second round, we have nearly 5000 students. 120 contributors from 22 countries have made this course series dynamic and highly interactive. Our students come from 135 countries! The courses are self-paced and free.



*ABLE101x – Through my Eyes* focuses on the stories of people with intellectual disability around the world, and their families and supporters. Over four parts, students will look at the barriers and enablers to healthcare for people with intellectual disability, their experience of specific syndromes and communication difficulties, and how they stay healthy. Students will listen to family members speaking about complex care, rare syndromes, early death, and planning for independence. The final component focuses on the history of treatment, the impact of rights' movements on healthcare delivery, common health conditions, and health promotion.

<https://www.edx.org/course/through-eyes-intellectual-disability-uqx-able101x-0>

*ABLE201x – Well and Able* examines the specific physical health issues that affect people with an intellectual disability including, oral health, syndrome specific health issues, health communication, especially for non-verbal patients, sexual health, and interactions between tertiary and primary healthcare systems. There is a special section on complex care including issues associated with aging and spasticity, and the health impacts of epilepsy.

<https://www.edx.org/course/well-able-improving-physical-health-uqx-able201x-0>

*ABLE301x – Able-Minded* focuses on the mental health issues of people with intellectual disability. Students learn about the complexities of diagnosing mental health issues in people with intellectual disabilities and the types of disorders, assessments, screenings, and treatments used. There is a special focus on the legal and ethical complexities in health practice with patients who often require substituted consent.

<https://www.edx.org/course/able-minded-mental-health-people-uqx-able301x-0>



**Here are some of the interesting comments and insights from students of the courses:**

### **USA**

I know personally, raising my son, how hard it is for people with disabilities to be accepted. We live in the Tennessee, USA, the options are getting much better for help but it's people in general who are cruel. Adults need to teach their children to be more accepting & teach them to treat everyone the same, to offer friendship & help against others who are being mistreated.

As quality of life is probably the most important aspect of caring for an individual with I/DD, quality of death should also be considered. I would try to communicate with Ray about how he feels, both physically and emotionally, have pain medication administered, and mostly just be there with him. I was with my father as he was dying of cancer, and when he could no longer speak it was difficult to determine his needs. But I think what he appreciated most was that I was there by his side through to the end.

### **NIGERIA**

In my country there is no mainstream support in place for aging people with or without disabilities. Children generally house their aging parents disabled or able, and cater for them by themselves. Such responsibilities usually fall on the wives and can be very stressful at times but that is our norm.

### **LEBANON**

In a third world country like mine, mental health is taboo. Poor people are treated in very large hospital type institutions. Private consumers usually stay at a wing of a regular hospital specialized in mental health.

### **NEPAL**

I have seen some of who are having mental issue, they are not getting proper counseling from their family, relatives, society and even from governmental support.

Miriam Taylor  
Education Coordinator

## QCIDD links to view at your leisure

- QCIDD's website— <https://qcidd.centre.uq.edu.au>
- QCIDD's person-centred website— [www.qcidd.com.au](http://www.qcidd.com.au)
- ASK Diary (Advocacy Skills Kit Diary) <https://itunes.apple.com/au/app/ask-diary-advocacy-skills/id1095955087?mt=8>
- QCIDD's YouTube channel—  
[https://www.youtube.com/channel/UChCUpCHdvnHqAf8SBOuV\\_tA](https://www.youtube.com/channel/UChCUpCHdvnHqAf8SBOuV_tA)
- 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—  
<https://qcidd.centre.uq.edu.au/resources/diabetes-point>
- Scared of going for blood tests or CT scans or X-rays? Desensitise yourself here—  
<https://qcidd.centre.uq.edu.au/resources/desensitisation-programs>
- Having a yearly health check keeps you well, and here's why—  
<http://eshop.uniquet.com.au/chap>
- Tweet to @QCIDD for up to-date news and ideas
- Facebook—<https://www.facebook.com/qcidd.uq>

## 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.qld.gov.au/\\_data/assets/pdf\\_file/0008/460088/final-systemic-advocacy-report-deaths-in-care-of-people-with-disability-in-Queensland-February-2016.pdf](http://www.justice.qld.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 with Disability—  
<https://www.futurelearn.com/courses/working-with-disability>
- Australian Association of Developmental Disability Medicine (AADDM)—<http://aaddm.com.au/>
- Australasian Society for Intellectual Disability—<https://www.asid.asn.au/>