

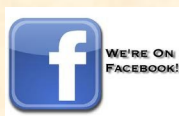


Located at
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Annerley Rd,
South Brisbane
61- 07-31632412
qcidd@uq.edu.au



Jan—Mar 2013

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.



Dear QCIDD Supporters,

Hello and welcome to 2013!

This year has started off with a big research BANG! We have three PhD students about to start on separate projects including the long term follow up of the CHAP, an evaluation of a Walk and Talk Program, and a roll out of Health Clinics for people with intellectual disability. We're also farewelling six summer scholarship students who have been working hard over the past three months on QCIDD research projects.

QCIDD CLINIC UPDATE

Our waiting list for the clinic is well into 2013! Prof Lennox is booked until November, Dr Lane until March, Dr Eastgate mid March, and Dr Franklin is booked until December 2013. Don't let this stop you from sending in a referral or requesting appointments, be sure to ask the waitlist time for the doctor that you will be seeing.

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

The staff of QCIDD hope all of our colleagues, friends and supporters had a very Merry and safe Christmas and New Years.

QCIDD is looking forward to working with you in 2013.



What's new for QCIDD in 2013?

In 2013, three PhD students will join our QCIDD research team. They will work on the following topics:

"Follow-up of a comprehensive health assessment of adults with intellectual disability in a large non-government organisation"

The Comprehensive Health Assessment Program (CHAP) has been shown to be effective in improving health outcomes for people with intellectual disability, especially in neglected health areas such as immunisation, vision and hearing checks. For more than ten years, participants of the original CHAP randomised trial have received an annual or biennial health assessment. This study will gather evidence as to the optimal time interval between CHAP reviews. It will also gather data on the administration of this widely used tool.

"We can talk while we're walking" views of a walking and social support program

People with intellectual disability report low levels of physical activity and community participation. *Walk and Talk* is a community-based walking and social support intervention for people with intellectual disability that is currently being rolled-out by a Brisbane service provider. The program pairs a person with intellectual disability with a walking partner (a community volunteer). This walking pair will be supported to walk at least once a week around their local neighbourhood. This PhD research will focus on the evaluation of this project using qualitative and quantitative public health methodologies. The researcher will investigate perceptions of walking, and facilitators and barriers to participation in health promotion programs.

"The Evaluation of a Pilot Student-run Multi-disciplinary Health Promotion Clinic at the Workplace of Adults with Intellectual Disability"

Multi-disciplinary health professional students from the University of Queensland will work collaboratively with employees of Endeavour Foundation Business Industries, including those with mild intellectual disability, to design and implement brief, appropriate and accessible workplace health promotion interventions. Students will provide participants with education, basic assessments, take-home information and a Health and Wellbeing Passport to encourage further interest in and uptake of health promotion messages. Students and participants will be followed longitudinally to assess changes in attitudes, knowledge, self-efficacy and health outcomes.

Other major research at QCIDD will include the continuing analysis of the data of prisoners with an intellectual disability from a recently completed large randomised controlled trial of a health-based intervention to evaluate health outcomes and patterns of re-offending for 15,000 adult prisoners in Queensland. A subsequent data linkage study of this cohort is also underway. Similarly the data from the Ask study, a 5 year NHMRC funded project that aimed to improve the health of adolescents with an intellectual disability is being analysed. The needs of these adolescents were often quite complex and by working with this population QCIDD become more aware of the problems faced by adolescents and their families as they loose support from paediatric services. We are also part of an on-going study using this cohort in collaboration with researchers in WA seeking to explore other challenges faced and outcomes achieved by young people as they move from secondary school into adult life. This experience will be valuable as we proceed with a new, collaborative research study that aims to better understand and inform improvements to childhood and adolescent transitions into primary health care for people with intellectual and developmental disability. This project will aim to audit the current transitions experiences of children and families and carers in Brisbane; better understand the barriers and facilitators to a 'successful' transition into primary health care; and determine the effectiveness of a health intervention package consisting of the CHAP tool and Ask health diary in improving transitions into primary health care for children with intellectual and developmental disabilities.

Summer Scholarships



During the recent university vacation period we had six students come to QCIDD under the UQ Summer Research Program which provided an opportunity for them to gain research experience working alongside academics and researchers. Coming to QCIDD also made these young people, many of whom were medical students, more aware of the problems faced by people with intellectual disability. They assisted on various on-going projects and in some cases initiated new research. A systematic review on the impact of hand-held health records has been submitted for publication and several other papers are being prepared as a result of their work. Feedback from students suggested that they enjoyed their time with us and that they gained much from the experience.

Students and Project Title:

Mathuja Bavanendrakumar (supervisor: Margo Lane)

A systematic review of physical health outcomes of adults with intellectual disability

Abhishta Bhandari (supervisor: Kate van Dooren)

Substance use, and drug related risks and harms in prisoners with and without intellectual disability

Michelle Nguyen (supervisor: Rob Ware)

The impact of hand-held health records for people with intellectual disability: a systematic review of evidence

Taha Othman (supervisor: Lyn McPherson)

The transition from secondary school to adulthood: experiences and life outcomes for youth with an intellectual disability and their families.

Kiri Patton (supervisor: Lyn McPherson)

Parenting stress in families with adolescents with an intellectual disability.

Murray Robertson (supervisor: Cindy Nicollet)

Long-term changes for adults with an intellectual disability in life quality, adaptive and maladaptive behaviour and choice-making 15 -20 years post-deinstitutionalisation: Challinor deinstitutionalisation revisited

AUSHSI GRANT – eHealth records

Late last year, QCIDD was awarded a grant to investigate people's experiences and expectations of electronic health records. Everyone in Australia is now eligible to register for a national eHealth record, which places health information online to be shared across different health professionals. QCIDD is keen to ensure that people with intellectual disability are not excluded from this system, because it is too difficult to manage or unwieldy for carers and support workers. We will be interviewing around 30 people to find out what they think of eHealth records. If you're interested please contact k.vandooren@uq.edu.au

Walk and Talk

QCIDD recently attended the Endeavour Foundation's induction program for volunteers of the pilot Walk and Talk program. Volunteers will be paired with an Endeavour Foundation client and the walking pair will walk around the neighbourhood for at least half an hour a week. QCIDD will be evaluating the program. It was exciting to see the program kicking off with enthusiastic and eager volunteers from all walks of life. A big thank you to Kim from Endeavour who has put in many hours developing the program. If you'd like to find out more about this program, contact k.vandooren@uq.edu.au.

Of Interest:

- ∞ <http://www.childmind.org/en/posts/articles/2013-1-15-animals-help-children-dogs-and-therapy>
- ∞ <http://www.sleephealthfoundation.org.au/>
- ∞ <http://www.childmind.org/en/posts/articles/2013-1-7-adhd-teenagers>
- ∞ <http://www.bbc.co.uk/news/technology-19389396>
- ∞ http://info4carers.com/images/docs/2011%20You%20Are%20Not%20Alone_eBook.pdf
- ∞ <http://www.bbc.co.uk/news/health-19293190>
- ∞ <http://www.abc.net.au/radionational/programs/healthreport/care-track-study/4133230>
- ∞ <http://www.abc.net.au/radionational/programs/lifematters/health-in-criminal-justice-system/4200354>
- ∞ <http://www.abc.net.au/radionational/programs/newdimensions/nds-30-07-0205-233437/4092654>
- ∞ <http://www.abc.net.au/radionational/programs/scienceshow/helicobacter-pylori-e28093-from-discovery-to-pharmaceuticals/4129456>
- ∞ <http://www.aljazeera.com/programmes/insidestoryamericas/2012/08/2012898171744208.html>
- ∞ <http://www.aljazeera.com/indepth/opinion/2012/02/20122184025836885.html>
- ∞ <http://www.aljazeera.com/indepth/opinion/2011/07/20117313948379987.html>
- ∞ http://www.wwild.org/Downloads/how_to_hear_me_%20WWILD.pdf
- ∞ <http://www.redcross.org.au/retirement-handbook.aspx>
- ∞ <http://www.abc.net.au/radionational/programs/bigideas/big-ideas-22-october-2012/4320786>
- ∞ http://www.sbs.com.au/ondemand/video/2309847829/Girl-with-Down-Syndrome-features-in-ad?utm_source=Latest
- ∞ <https://open.abc.net.au/posts/i-am-peter-i-am-an-artist-and-a-writer-97dn3cf>
- ∞ <http://www.childmind.org/en/posts/articles/2013-1-15-animals-help-children-dogs-and-therapy>
- ∞ <http://www.sleephealthfoundation.org.au/>



Fellow of the Australasian Society for Intellectual Disability.

Nominated by his Queensland colleagues, Professor Nick Lennox was awarded the honorary title of “ASID Fellow.” This is in recognition of his significant achievements during the last twenty years, working on behalf of people with intellectual and developmental disability as a researcher, educator, advocate and clinician.



CRC for Living with Autism Spectrum Disorders

The Federal Government's announcement on 16 February 2013, establishing a Cooperative Research Centre (CRC) for Living with Autism Spectrum Disorders, is set to revolutionise the way Autism research is undertaken in Australia and will transform the lives of more than one million Australians.

The Autism CRC, to be based at Long Pocket in Brisbane in association with the University of Queensland, will be the world's first national, cooperative research effort directed towards Autism.

The implementation of a highly innovative “whole-of-life” research portfolio will deliver a continuum of support required for people with Autism to participate successfully in education, employment and all facets of the community.

The core participants in the Autism CRC will be:

- Autism Queensland Inc.
- University of Queensland
- Queensland University of Technology
- Griffith University
- Mater Medical Research Institute
- AEIOU Foundation
- Department of Education, Training and Employment Queensland
- LaTrobe University
- University of NSW
- Curtin University
- University of Western Australia

Autism Spectrum Australia (ASPECT)

QCIDD has been part of the development of this application and will lead Program 3.3.

Chronic Disease & People with Intellectual Disability

We recently organised two panel discussions on *Chronic Disease & People with Intellectual Disability*. Expert panel members from peak organisations discussed how these specific chronic diseases impact on people with intellectual disability :

- | | |
|---------------------------------|--------------------------------------|
| <input type="radio"/> Asthma | <input type="radio"/> Obesity |
| <input type="radio"/> Diabetes | <input type="radio"/> Epilepsy |
| <input type="radio"/> Arthritis | <input type="radio"/> Mental Illness |

Australians with intellectual disabilities have poor health. They are at risk of dying up to 20 years earlier than the general population. They have high rates of co-morbid physical and mental health problems. There are five chronic diseases identified for national attention, namely asthma, cancer, diabetes, cardiovascular disease, and arthritis. These diseases are experienced by people with intellectual disability. The Chronic Care Plan Initiative also focusses on renal dysfunction, obesity, epilepsy and mental illness.

The sessions were well-attended and feedback was really positive:

"The take home message for all people caring for people with intellectual disability is go to the GP and check the person's health!"

"Chronic illness can underlie a great deal of quality of life issues for people with intellectual disability."

"I will look into these issues, epilepsy, arthritis, mental illness!"

Here are some of our excellent presenters:



Helene Frayne,
General Manager,
Arthritis Queensland



Yvette McMurtrie, Client Service
Coordinator, Epilepsy Queensland



Dr Cathy Franklin,
Psychiatrist, QCIDD