



Located at
the Mater Hospital,
Level 2, Aubigny
Place
South Brisbane
61- 07-31632412
qcidd@uq.edu.au



THE UNIVERSITY
OF QUEENSLAND

Jan—Mar 2014

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.

From the Director

Dear QCIDD Supporters,

As I haven't done so already I would like to take the opportunity to report on my travels last year. As previously mentioned in an earlier QCIDD newsletter, I was invited to present the paper *Promoting Physical Well-Being in Persons with Intellectual and Development Disabilities* at the 6th International Colloquium of the International Association of Catholic Bioethicists (IACB) in Italy from 9-14 June. This presentation allowed me to draw to the attention of the Catholic Church at its highest level the issues that face people with intellectual and developmental disability. At the conclusion of my paper, I called upon the Colloquium to use whatever mechanisms that are available to insist governments direct substantial resources to improve the physical and mental health and wellbeing of children, adolescence and adults with intellectual and developmental disability.



Following on from this I flew to the UK where, based at the University of Cambridge as Senior Visiting Research Fellow, I met with researchers from all over the UK. I become a partner in an established grant with Researchers based at University College London to evaluate the implementation of health checks in England and Wales. QCIDD's research over the last fifteen years has been central to the implementation of health checks throughout the world and I feel this experience will be valuable as we strive to implement the CHAPs more widely across Australia.

In another important collaboration we have developed a group of researchers from twelve countries to compare mortality of people with intellectual disabilities across the high resource countries. We are currently working together on a paper with a focus on the comparisons of reporting on the death of people with intellectual disability between the countries. In the future we hope to refine this comparison of mortality and add other markers of health and wellbeing.

I was then able to spend a few weeks at Raboud University at Nijmegen in The Netherlands before giving the Keynote Presentation at the MAMH and the International Association for the Scientific Study of Intellectual and Developmental Disabilities (IASSID) Health Special Interest Group meeting *Health Inequity: From Evidence to Action*. I returned home via Canada where I met with colleagues from the University of Manitoba, the University of Toronto and Queens University in Kingston Ontario regarding the implementation of the CHAP, transition of care and educational initiatives. Here I was asked to do a number of presentations including the Keynote Address at the Health and Wellbeing in Developmental Disabilities Conference and a presentation *Nudging the Health Care System* for families at the Autism Foundation in Toronto.

Wishing you all the best for 2014

Nick Lennox
QCIDD Director

QCIDD CLINIC UPDATE

Our waiting list times for Dr Cathy Franklin should improve from March 2014 as we have a registrar attending our clinic. Until then please see below for our current waiting list times:

- Prof Lennox 4–6 months,
- Dr Margo Lane 4–6 months,
- Dr Gillian Eastgate 4–6– months,
- Dr Cathy Franklin 14 months.

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.

What's new for QCIDD in 2014?

QCIDD Tutors

The Queensland Centre for Intellectual and Developmental Disability (QCIDD) aims to improve the health of people with an intellectual disability. The Centre achieves this objective by providing clinical services, conducting research, and educating the sector.

One of the Centre's teaching focuses is on providing education to tertiary students across a range of disciplines. To enhance the effectiveness and impact of this education, we include the expertise of adults with an intellectual disability and their families to speak about their experiences as a person with a disability as well as providing insight into how health services can be improved for people with an intellectual disability.

Research looking at the effectiveness of this teaching practice has demonstrated that students across different disciplines find the experience invaluable. From the perspective of changing attitudes and practice, research has indicated that medical students experiencing direct contact with a person with an intellectual disability are more likely to change the practice of future medical practitioners.

The structure of our teaching approach is to provide an introduction and overview of the history of intellectual disability as well as the history of medical treatment. Staff from QCIDD also explore improvements in medical practice and health promotion and provide research examples to demonstrate these aspects. Adults with intellectual disability who participate in the lecture value-add by providing their own personal perspectives on health care as well as discuss skills that undergraduate and postgraduate students can develop that will enhance their practice in the future, working with adults with intellectual disability.

If you, or someone you know could be a candidate as a QCIDD tutor, please contact the Education Coordinator at qcidd@uq.edu.au or (07) 3163 2446.

Summer Research Scholarship Students

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. Over the 2013/14 summer vacation period, three of our 2012/13 scholars returned to QCIDD to work on projects commenced the previous year. They were:

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”

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”

Two new students joined us for the 2013/14 summer to work on two new projects:

Thushani Adikari (supervisor: Nick Lennox and Lyn McPherson)

“Velo-cardio-facial syndrome in adults: a scoping review”

Carmel Blackburn (supervisor: Miriam Taylor)

“The experience of families of adults with specific genetic syndromes: Synthesising family conversations with the literature”

More about Carmel

Carmel Blackburn is commencing her third year of a Bachelor of Nursing at UQ in 2014. When she is not buried in course texts and journal articles, or on prac around the Mater, you will find Carmel working with Mater DART Paediatrics looking after ventilator dependent kids in their home, case working and counselling at Drug Arm in Ipswich, or chasing her two little gentlemen and a grumpy cat at home.

She is currently preparing an article for publication with Miriam Taylor on their findings after Carmel interviewed the parents of adult children with rare genetic syndromes. She looks forward to a continued involvement with QCIDD in the future and hopes to pursue an Honours Degree in 2015.





AADDMM—QCIDD Conference 2014

Health and Autism Across the Lifespan

Friday 22 August 2014

<http://aaddmqciddconference2014.wordpress.com/>

In association with the Queensland Centre for Intellectual and Developmental Disability (QCIDD), the 2014 AADDMM Conference is to be held at the Mater Hospital in Brisbane on Friday 22nd August. The theme of the conference will be *Health and Autism across the Lifespan*.

Conference

Keynote Address by Dr James Morton - A father's Vision into the Future of Health Care of his Son

This address will be followed by lead clinicians discussing approaches to key physical and mental health issues through the life span. The conference will have a very pragmatic focus for clinical practice. Delegates will be Australian and New Zealand medical and allied health practitioners who are seeking ideas on how to improve their clinical services for people with Autism. There will be only one stream so that delegates can enjoy the breadth of knowledge presented during the day.

The sessions themes will be as follows:

- Medical assessment and care and psychological intervention in the first 6 years
- Health, educational and psychological management in the school years
- Integration into work + Global picture of CRC Autism
- Adulthood and complex health needs Panel discussion with scenarios
- Healthcare and growing older

The Registration brochure is attached and the preliminary program is available on the conference website:

www.aaddmqciddconference2014.wordpress.com/

Pre-Conference Workshop

Dr Kate Sofronoff - Evidence Based Interventions for Autism Spectrum Disorders in the School Years.

Thursday 21st August, 2014, 1:00-5.00pm, Hotel Diana

The workshop will take a practice focused approach and present information, evidence and resources for practitioners working with children with ASD and their families

Welcome Function

This will follow the Pre-Conference workshop at the Hotel Diana and will be open to both Conference and Workshop Delegates. It will provide an excellent opportunity to network and meet some of the speakers.

For any further information please see our website or contact Jenny Curtis on aaddm@outlook.com

In late 2013 QCIDD had a visiting Registrar, Dr Willemijn Hensbroek



Dr Willemijn Hensbroek (Visiting Registrar in Intellectual Disability Medicine, the Netherlands) spent a great three weeks at QCIDD.

She attended weekly clinics and clinic meetings, met with parents and advocates at CRU (Community Resource Unit). She visited and talked with people at the Healthy Living sessions at Campbell's Club, afternoon tea at Common Ground and went along on the night time run with the Mater Homelessness Health Service, all courtesy of Micah Projects.

Willemijn was invited to attend a Family Planning Queensland event in Ipswich and learnt a lot about the NDIS from National Disability Services (Qld). She met and had a long session with the QLD Public Advocate and the Adult Guardian.

She also met with several people with disabilities and their families during home visits.

Before departing, she gave an interesting presentation to a varied audience on the differences and similarities between the Australian and Dutch healthcare systems for people with intellectual disability.

We wish her all the very best on her next ventures.

Healthy Living at Campbell's Club

Every Thursday Morning

This initiative is a collaboration between Queensland Health, Micah Projects and QCIDD. For many years, Micah Projects has run Campbell's Club every Monday and Thursday at Trinity Place in Woolloongabba for between 50 and 80 people who are vulnerable, and who live in private residential services like hostels. Many people have intellectual disability.

QCIDD and Queensland Health have worked with Micah for two years now to provide health information to people who use Micah services. People with intellectual disability, especially those who live in vulnerable circumstances, have extremely poor health status and minimal internal or other resources. They are prone to severe chronic disease including cardiovascular disease, diabetes, and asthma due to high risk factors such as obesity, sedentary activity, nutrition, and smoking as well as entrenched self-neglect. Long histories of institutionalisation and marginalisation mean they experience few social supports, sexual and physical abuse, and lack of pleasure and life-skills in ordinary activities like eating, walking and other exercise. Before seeking medical advice, they often allow their health to deteriorate to such a point, that they will then need to go to hospital Accident & Emergency (A&E) Department, which could have been provided earlier by primary care. This is exacerbated by their lack of social support around caring for their own health. Providing information on healthy lifestyle and self-management strategies will improve their general health and also provide them with strategies for self-management, including early interventions with a GP, and this may well reduce A & E presentations and hospital admissions for this group. In October 2013, we again launched into another unfunded project with Micah and Queensland Health to provide health information to people who attend Campbell's Club on Thursdays. We asked participants what health topics they wanted to hear about and came up with a very long list! We line up the speakers from health and community services. We provide them with a speaker's pack to give them ideas. The audience challenges the speakers to be creative and to keep their messages simple, so it is a great way to expose mainstream services to working with people with disability. The speaker must use simple, plain language and avoid jargon. Most participants have limited literacy so speakers have to use imagery and memorable messages.



To date, our guest speakers have covered these topics:

- ~ Going to the doctor ~ Finding a good doctor ~ Sugar in soft-drinks and milk drinks ~ The healthy plate
- ~ Arthritis and osteoporosis ~ What is breast cancer? ~ Treating breast cancer ~ Depression and anxiety

We are committed to keeping up the speakers on health topics every Thursday, rain hail or shine!

If you have any questions or suggestions, you can contact:

Troy Hakala at Qld Health on 07-3169 9956 or troy_hakala@health.qld.gov.au

Miriam Taylor at QCIDD on 07-31632446 or m.taylor3@uq.edu.au



CALL FOR NOMINATIONS ASID QLD HONOURS STUDENT SCHOLARSHIPS FOR 2014

This newly-established scholarship, sponsored by ASID Queensland, is open to Honours degree students in any program or school. Up to \$1000 will be available to assist the scholarship holder to complete an approved research project in the field of developmental/intellectual disability research. A total of three scholarships are available in 2014.

Conditions of the award

1. Applicants must be:
 - a. A current student member /member of ASID
 - b. A current candidate for an Honours degree
2. The approved project must add evidence-based knowledge in the field of developmental/intellectual disability
3. The successful applicant will be requested to present the results of their research at an ASID QLD forum
4. The successful applicant will send a written report to the ASID QLD Committee and prepare a report to appear in the IDA Magazine on completion of their project
5. Funds will be disbursed after the ASID Queensland Committee has been furnished with a copy of the Research Ethics Committee approval
6. Funds will not normally be approved for the purchase of equipment
7. The decision of the ASID QLD Committee is final and no further correspondence will be entered into.

Interested students should send the completed application form and an abstract of no more than five pages (include sections covering Background, Research Questions, Research Methods, Time line for critical milestones and expected date of completion and Budget) to:

Secretary, ASID Queensland
PO Box 3224
South Brisbane BC QLD 4101

The closing date for submissions is 11 April 2014.

If you would like to apply, please contact Hamish Millard on Hamish.millard@tpg.com.au

Sister Regis Mary



Miriam Taylor (Education Coordinator), Kate van Dooren (Lecturer), and Cindy Nicollet (Behaviour Support Consultant/Associate Lecturer) recently visited Sr Regis Mary, a long time supporter of QCIDD.

Sr Regis shared stories about the beginnings of the Mater Hospital and the early days of her career as a microbiologist. Sr Regis Mary was one of the first to introduce cytogenetics into a laboratory. She also has extensive experience as an ethicist, and geneticist and was the former Director of the Queensland Bioethics Centre. She has also been the member of many Human Research Ethics Committees, the NHMRC Australian Health Ethics Committee and a member of the NHMRC Gene and Related Therapies Research Advisory panel.

We also took the opportunity to share with Sr Regis Mary the various projects that QCIDD is currently engaged in. Overall, it was a pleasant and enlightening visit which we hope to do again.

The Metro South Intellectual Disability and Acquired Brain Injury Assessment Partnership involves Metro South Health, QCIDD, West Moreton-Oxley Medicare Local, Griffith University, and Metro South Medicare Local.

The Partnership is looking to explore:

The social determinants of health which impact on this population

Local system usage experiences and issues which create barriers to appropriate service access

Early intervention issues

Gaps in data and health care system data needs

Best practice approaches and models of care

The partnership should have the assessment finished in mid-2014.



Syndromes and Health

We held our first webinar for service providers in February, a full day workshop on Syndromes and Health, and 38 people attended with five present on webinar.

QCIDD spoke about why health assessments are important and then Yvette McMurtrie, the Client Services Coordinator for Epilepsy Qld spoke about the major health concerns for people with specific syndromes and epilepsy.

Dr Kate van Dooren, our Lecturer in Health and Intellectual Disability, spoke about Autism Spectrum Disorders including Fragile X and the associated health issues of concern.

Dr Kerryn Bagley, from National Organisation for Foetal Alcohol Spectrum Disorders, has completed a number of internationally recognised FASD diagnostic and intervention training programs and currently works in private practice providing training and consultation to professionals and support to families affected by FASD. She gave a very interesting presentation.

Dr Catherine Franklin, from QCIDD, spoke about Prader Willi Syndrome and associated health issues.

Lysandra Warren, from the Queensland Angelman Association, spoke about being a mother and raised our awareness of the syndrome and associated health issues.

Karen Innes-Walker, from the QUT Institute of Health and Biomedical Innovation, spoke about her two children. Her daughter has Smith Magenis Syndrome, and her son has teenage boy syndrome. She spoke about the most current research into Smith Magenis syndrome.

Sean Kenny, of the Turner Syndrome Association of Australia, and father to a daughter with TS decided that rather than sit on the sidelines he would get involved. He has been the National President for the TSAA for 7 years. He and his wife, Korina, are active advocates for people with Turner Syndrome and their families.

Clare Stuart is the Project Manager at The Australasian Tuberous Sclerosis Society, the only organisation in Australia and New Zealand that represents families affected by the genetic disorder Tuberous Sclerosis Complex (TSC). Clare is passionate about improving the way health decisions are made. She presented via webinar from Sydney even with two littlies around her feet during the presentation.



Bill Callaghan first became aware of Rett syndrome in 1986 as that was when his 15 year old daughter, Joanne, was given the diagnosis. However, it wasn't until a year later that he met another family whose daughter had the condition following a story about them published in the Australian Women's Weekly. One thing led to another after that meeting with the result that Bill and several other parents formed the Rett Syndrome Association of Australia in 1989 which was based in Melbourne. He has been its President ever since. His daughter Joanne passed away in 2004. Bill was awarded the 'Medal of the Order of Australia (OAM)' in 2012 for his service to the Rett Syndrome Association of Australia. We have asked Bill to speak twice now about Rett Syndrome and health, and he has come both times, with enthusiasm. It never occurred to us that Bill lives in Victoria! He has come all this way without a word both times!

We are privileged to have so many wonderful parent and family advocates who willingly give us their time and expertise.

Congratulations Russell!!!

Russell Booysen has been selected to represent Australia at the World Down Syndrome Championships for a second time!



Russell is pictured here with Geoff Huegill at the Australian Nationals in 2013, where he won 2 Gold and a Bronze Medal.

For more information about the Championships which will be held in November 2014 visit <http://www.dsiso.org/>

Here are some links to view at your leisure;

- * Walk and Talk Program. They say 30 minutes of exercise a day is all it takes to keep a sound mind, body and soul, so would you take 30 minutes out of your week to walk and talk with someone with a disability to help theirs? Check out the ABC's news article on the program <http://www.abc.net.au/local/stories/2014/02/04/3937931.htm?site=brisbane>
- * Jacob Barnett is an American mathematician and child prodigy. At 8 years old, Jacob began sneaking into the back of college lectures at Indiana University-Purdue University Indianapolis. After being diagnosed with autism since the age of two and placed in his school's special education program, Jacob's teachers and doctors were astonished to learn he was able to teach calculus to college students. <http://tedxteen.com/talks/tedxteen-2012/111-jacob-barnett-forget-what-you-know>
- * On Thursday October 24, AEIOU Foundation welcomed Dr Temple Grandin to Toowoomba, where she shared rare, personal insights into her life, her career, and autism, including her thoughts on how children with a diagnosis can be best supported during their early years. It was with great delight that AEIOU welcomed more than 330 guests, including parents of a child with autism, individuals with an autism diagnosis, teachers, education and child care practitioners, allied health professionals, medical practitioners, and other members of the community. There are four videos for you to see <https://aeiou.org.au/aeiou-tv>
- * A new pilot program in Brisbane that has been giving special needs children the chance to experience one of the joys of an ordinary childhood, a sleepover, unfortunately is coming to an end. <http://www.abc.net.au/news/2013-10-25/dream-sleepover-club-runs-out-of-funding/5047404>
- * The classifications for Paralympic athletes with a physical disability are set to be overhauled with University of Queensland researchers developing objective machine based tests to measure impairments. <http://www.abc.net.au/news/2013-11-01/brisbane-researchers-to-revolutionise-paralympic/5065438>
- * How neuroscience can make you kinder. We can be healthier, live longer and make the world a better place by exploring our potential for compassionate behaviour. Neurosurgeon **James Doty** tells us about the surprising benefits of our better nature. <http://www.newscientist.com/article/mg22029390.300-how-neuroscience-can-make-you-kinder.html#.UoL14aN--71>
- * Sex and Disability: YES, the two can and should go together says Fran Vicary <http://www.theguardian.com/commentisfree/2014/feb/21/sex-and-disability-yes-the-two-can-and-should-go-together>