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THE UNIVERSITY
OF QUEENSLAND

January-March 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

A time to celebrate the start of the ABLEx MOOC series
BUT also a time to grieve the “potentially avoidable”
deaths of adults with intellectual disability in Queensland.



Dear QCCID supporters,

On Thursday 24th March we launched the ABLE XSeries of MOOCs. The Launch was great fun and attracted many key people including contributors Sean Fisher, Peter McMeekin, Peter Rowe and Allycia Staples. The Assistant Minister for Disability Services and Member for Ryan, the Hon Jane Prentice MP officially launched the ABLE XSeries. In addition Jodie Griffiths-Cook, the Public Guardian, members of the senior staff of the University of Queensland, including Acting Vice-Chancellor Professor Joanne Wright, Professor Nick Fisk, Professor John Prins and senior representatives from a number of government and non-government organisations attended.

ABLE 101x was timed to go live so that students could start the course on World Down Syndrome Day, Monday 21st March. However by chance the NDIS bilateral agreement was signed, and the Office of the Public Advocate (OPA)’s truly disturbing report was released, called “Upholding the right to life and health: A review of the deaths in care of people with disability in Queensland - A systemic advocacy report”.

I strongly recommend you go to the website 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 and download the pdf. It contains a succinct executive summary and recommendations.

Below is an edited version of my presentation at the launch which I wanted to share as it highlights what we have achieved at QCIDD and how much more needs to be done.

The Queensland Centre for Intellectual and Developmental Disability, or QCIDD, was established in 1997 in response to the poor health and healthcare of adults with intellectual disability in Queensland. We know from Australian research that people with intellectual disability die up to 20 years earlier than the general population and experience on average 5.4 conditions which are unrecognised or poorly managed. This situation has been confirmed by the centre’s research and the OPA’s report on the review of 73 deaths of people with intellectual disability in care. The report tabled in the Queensland parliament found “that over half of the deaths ... were unexpected, and that (of that number) two thirds were also considered to be potentially avoidable.”

As mentioned this comes at the same time as the signing of NDIS bilateral agreement. The NDIS represents an opportunity to improve the health and wellbeing of people with intellectual disability. However, as the Public Advocate observes, that without “A targeted strategy to educate and inform people with disability, their families/ carers, support staff, service organisations, health practitioners and the myriad of other relevant people and agencies in the broader community about health management and risk factors for people with disability”, the results will be catastrophic.

QCIDD has and will continue to work to address this concern. Over the last 19 years we have been supported by Queensland government funding and have value-added to this support through gaining competitive research and education grants, via the NHMRC, ARC and other bodies. We have delivered education and training to families, the disability sector and many different health professional groups, including GPs, psychiatrists, oral health practitioners and psychologists. Furthermore, we have delivered many world first ground breaking initiatives which have improved the healthcare of people with intellectual disability.

Notably these include the largest randomised controlled trials of health intervention strategies ever performed with people with intellectual disability. In these trials we found strong evidence of improved healthcare to support the implementation of primary care based health checks using the Comprehensive Health Assessment Program (CHAP); which is licensed and implemented by most state governments. This research work led to the establishment of Medicare items to support GPs to perform annual health checks and changed health policy, in Australia and overseas.

Another first is the development of the Advocacy Skills Kit, or *ASK* Diary, which has been shown to improve health advocacy. In 2014, an App of this diary was developed which was shortlisted for an Australian Innovation Challenge Award. The Ask App will be released soon through the University of Queensland by UniQuest.

AND now our latest world first - the ABLE XSeries on the health of people with intellectual disability. The key initiator and driver was, and continues to be, the QCIDD Education Coordinator, Miriam Taylor. It was Miriam who saw and recognised the opportunity offered by UQx and UQ to develop this series. I vividly recall Miriam looking across the table at me and saying “Nick, we should do this”. It was only then that we could see the huge potential of such an initiative. We could also see the disruption this would cause such a small team but felt the time and financial cost were worth the potential benefit. I cannot emphasise enough the enthusiastic support received from the UQx team led by John Zornig, and Project Manager Stella Winn, Learning Designer Linda MacDonald and Media Leader, Matt Petersen. Thanks to all of you, the UQx team, and especially, our 120 contributors from 21 countries.

This is the first part of ABLE XSeries journey for us. We want concrete outcomes; so the next stage is to oversee the widespread implementation in health and disability education in Queensland and elsewhere. The ripple effect is strong in this sector. Individuals and families share their knowledge and help each other, so we hope for the most profound impact in improving the advocacy skills of people with intellectual disability and those that support them, family and friends, to drive change in their healthcare worldwide.

Nick Lennox



Hon Jane Prentice MP, Vice-Chancellor Professor Joanne Wright,
Professor Nick Lennox, Ms Jodie Griffiths-Cook, Ms Miriam Taylor

More than 100 international experts have contributed to a world-first online course created by the Queensland Centre for Intellectual and Developmental Disability (QCIDD) and UQx.

ABLE XSeries is a set of three free Massive Open Online Courses (MOOCs) designed to help those in the healthcare industry to understand best practice for people with intellectual disability. The ABLE XSeries is the first edX course ever to address intellectual disability.



ABLE 101x “Through my Eyes” gives students an insight into the barriers and enablers in the lives of people with intellectual disability.

This health course focuses on the stories of people with intellectual disabilities around the world, as well as their families and supporters.

Topics addressed include various challenges in healthcare and aid received for people with intellectual disabilities. Personal experiences of specific syndromes, communication difficulties, and insights into how they stay healthy will also be discussed

Learners will also hear from family members as they discuss issues around complex care, rare syndromes, planning for independence and early death. The end of the course will focus on the history of treatment, the impact of rights’ movements regarding healthcare delivery, common health conditions, and health promotion.

This course is open to anyone, but will be of particular relevance to those in the field of advanced medical, allied health, and disability. This course can also be used as workforce education for medical professionals in this field.

To register: <https://www.edx.org/course/through-eyes-intellectual-disability-uqx-able101x#>!

ABLE 201x “Well and Able” – Improving the Physical Health of People with Intellectual Disability starts on 27th April 2016.

This health course will examine 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.



This course is open to anyone, but will be of particular relevance to those in the field of advanced medical, allied health, and disability. It can also be used as workforce education for medical professionals in this field.

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



ABLE 301x “Able-Minded” – Mental Health and People with Intellectual Disability starts on 25th May 2016.

This health course will focus on the mental health issues of people with intellectual disability.

You will 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 will also be a special focus on the legal and ethical complexities in health practice with patients who often require substituted consent.

This course is open to anyone, but will be of particular relevance to those in the field of advanced medical, allied health, and disability. It can also be used as workforce education for professionals who are interested in mental health.

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

A photograph of a modern interior hallway. The floor is covered in a patterned carpet with geometric shapes in shades of green, blue, and grey. On the right side, there is a dark armchair and a large screen displaying a space-themed image. The hallway leads to a brighter area in the background where a person is visible.

The space is bright, roomy and a very nice place for our clinicians to consult in. The waiting room has more space for wheelchairs and can accommodate a greater 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.**

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- Prof Lennox—12 months
- Dr Gillian Eastgate—8 months
- Dr Cathy Franklin—6 months
- Dr Oreste Theodoratos—2 months
- Dr Margo Lane —2 months

Page 4

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 **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

Summer Scholar

Andrea An joined us again this year during her 2015/16 summer vacation to continue working on the project “Co-production - Maximising self-esteem, self-worth, and autonomy” which looked at the *Healthy Living* project at “Campbell’s Club” as an example of co-production in action.

Healthy Living at Campbell’s Club is a collaborative initiative between Queensland Health, Micah Projects and QCIDD. Micah Projects have facilitated and run a social group called “Campbell’s Club” weekly for many years at Trinity Place in Woolloongabba. It is regularly attended by between 50 to 80 people who live in vulnerable circumstances. Many of the attendees have intellectual disability, and battle multiple physical and mental co-morbidities compounded by their vulnerable circumstances and complex social histories. *Healthy Living* is a health promotion program for adults with intellectual disability. Each week, a different presenter discusses a new health topic (including alcohol and other drugs, oral health, healthy food, and physical activity).

In 2014/15 Andrea began her project by doing a literature review on the inclusion of people with intellectual disability in research. She went on to conduct interviews with the participants, support workers and presenters at “Campbell’s Club” and transcribed those interviews. She returned as a 2015/16 Summer Scholar to complete the project. She analysed the data and has prepared a paper for publication using the results of her analysis. She found that not only are there few health promotion programs targeted specifically for people with intellectual disability existing in the literature, the inclusion of this group in the development of these programs is also lacking. While efforts have been made to include all stakeholders in the development of the *Healthy Living* program, further encouragement for the club members is recommended in order to promote their confidence to be involved. People with intellectual disability can be upskilled to better participate in the development and delivery of a health promotion program. The presenters should also be made to feel involved with the program. With more contribution from all the stakeholders, the *Healthy Living* program can go forwards and become a good example of co-production.

In recent years, we have had many medical students come to the centre as part of the Summer Scholarship Programme, and we are always delighted to see would-be doctors with the sensitivity that Andrea displayed for vulnerable people. We wish her well in her future studies.



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. QCIDD's current projects involve piloting an anxiety program for adults on the spectrum and a Comprehensive Health Assessment Program (CHAP) for adults on the spectrum with intellectual disability.

Anxiety Program for Adults

We are looking for adults on the spectrum to participate in a pilot anxiety program. The pilot 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 on the Spectrum with Intellectual Disability

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. Following the appointment, we are talking to the adult, if they are willing, their support person/s who attended the appointment, and their GP about their experiences of using 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.

We are also currently recruiting for three other national Autism CRC research projects:

1) Australian Longitudinal Study of Adults with Autism (ALSAA)

Researchers from the Autism CRC and the University of NSW are looking for adults on the spectrum 25 years and older and/or their carers/family members and adults from the general population to participate in a nation-wide questionnaire-based study which aims to improve understanding of life in adulthood for people on the spectrum.

If you would like to participate please go to this link: https://autismcrc.au1.qualtrics.com/SE/?SID=SV_1UoHxIKX4M0WRo1

Please see a short Youtube clip describing this study: <http://youtu.be/50rKjEtxb3M>

For more information please contact Dr Kitty Foley or Ms Jane Hwang on (02) 9385 0620 or autismcrc@unsw.edu.au

2) 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)

3) Help create an autism-friendly workplace

A new research project is underway to help identify ways to adapt the workplace to better suit the individual needs of employees on the autism spectrum. Researchers from the Autism CRC and Curtin University are seeking input from employers, managers and/or supervisors who currently have adults on the autism spectrum working within their organisations. The results of this project will be used to develop a workplace tool that will assist employers to adapt the workplace to better meet the needs of their employees on the autism spectrum, leading to better employment outcomes for all.

For more information or to register your interest in participating, please contact: Melissa Scott on 041 603 2771 or melissa.scott@curtin.edu.au.

QCIDD links to view at your leisure

- QCIDD's website—<https://www.som.uq.edu.au/research/research-centres/queensland-centre-for-intellectual-and-developmental-disability.aspx>
- QCIDD's person-centred website— www.qcidd.com.au
- 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-uqx-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.nds QLDprojects.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/MSvfo0>
- 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—<https://www.som.uq.edu.au/media/217592/CHAP%202010%20brochure.pdf>
- 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
- 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>