



Located at
the Mater Hospital,
Level 2, Aubigny
Place
South Brisbane
61- 07-3163 2412
qcidd@uq.edu.au



THE UNIVERSITY
OF QUEENSLAND

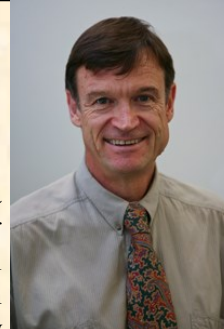
April-Sept 2015

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.

A message from the Director:

Dear QCIDD Supporters

2015 has been a busy year for us all here at QCIDD. Our clinicians are now settled in our new clinic area in the recently renamed “Salmon Building” (previously known as the Mater Children’s Hospital). Mater Health Services has been supportive of QCIDD since its inception. During this year Dr Cathy Franklin has been appointed as Senior Medical Officer with Mater Health Services and a Research Fellow with Mater Research Institute—UQ. This support has provided a unique opportunity for Cathy to not only continue her working relationship with QCIDD, but also allow continuity of care of her QCIDD patients.



In addition to our normal teaching, our educational focus has been on the development of our Massive Open Online Course (mooc). Filming for this has seen me interview world experts in intellectual disability from the US, UK and the Netherlands, as well as Special Olympics staff and athletes. In India, I had the privilege of speaking with Ms Pramila Balasundaram, Founder-Member of Samadhan Social Welfare Society, who took me to visit families from very poor backgrounds in New Delhi, who had very young children with intellectual disabilities. You will find an article describing the course content in this newsletter.

During my trip I also presented at the Pacific Rim Conference on Disability & Diversity on health interventions for people with intellectual disabilities and gave two presentations at the 2015 IASSID American Regional Conference on our current research.

In the Netherlands I presented with Dr Esther Bakker at the National Meeting of Intellectual Disability Physicians. I also had the pleasure of giving the keynote presentation at a farewell event for Prof. Dr. Henny van Schrojenstein Lantman on her retirement. Over the years QCIDD has often worked with Henny and her team. Henny has spent her whole professional life as an intellectual disability physician, and it was through her practice that she was inspired to seek out the reasons why people with intellectual disabilities had more health problems than average patients, and then what could be done to diminish these problems. The mission of her research, like that of QCIDD, has been to support an adequate health care provision for people with intellectual disabilities living in the community.

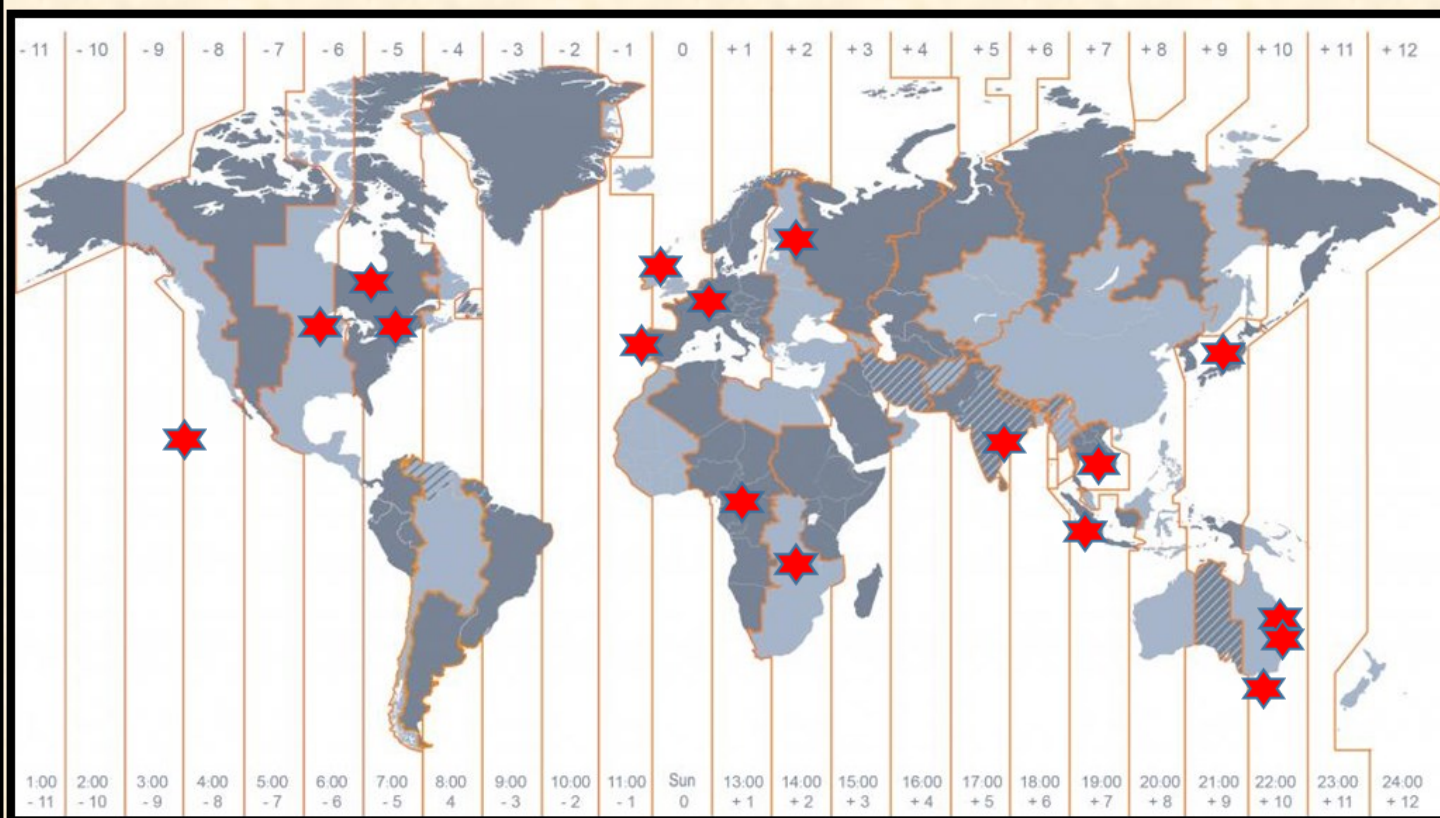
Much of QCIDD’s research this year has been in relation to autism, due to our involvement in the Cooperative Research Centre for Living with Autism Spectrum Disorders (Autism CRC). This has been led very ably by our Post-Doctoral Research Fellow, Dr Kate van Dooren, who has just gone on maternity leave. We are working across a number of areas of research relating to the needs of adults on the autism spectrum. Two student projects are described later in this newsletter.

Best wishes for the remainder of 2015.

Nick Lennox



Our Massive Open Online Course (mooc) *Able x-series - Intellectual Disability Healthcare around the world* is definitely coming together. The filming for the mooc is almost finished! To get in-depth interviews with people with intellectual disability, their families, supporters and various clinicians and academics, Nick Lennox has travelled far and wide, and Miriam Taylor has been interviewing people via skype or in person closer to home. This map shows where our contributors come from:



101x—*Through my eyes*—Focus on the stories of people with intellectual disability, their families and supporters around the world. It is open to everyone and also suitable for first year undergraduate medical and allied health students.

201x—*Well & able*—Focus on common health issues for this population, the importance of health assessments, guides for health promotion, oral health, syndrome specific health issues, communication, sexual health, and interactions between tertiary and primary healthcare, ageing and epilepsy. This course will be suited to workforce education (medical practitioners, nurses, psychiatrists, therapists, etc), senior medical and allied health students, and disability professions.

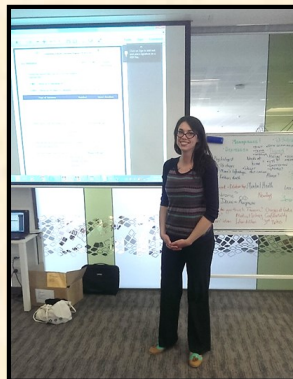
301x—*Able-minded*—Focus on mental health issues, disorders, mental health assessments and screenings, challenging behaviours, treatments, legal and ethical issues. This course will be suitable for workforce education (medical practitioners, nurses, psychiatrists, therapists, etc), senior medical and psychology students, psychiatry and other medical registrars, psychologists, and disability professionals.

Healthy Living changed to broaden impact and involve more mainstream services (collaboration with Micah and Qld Health) at the Campbell's Club (fortnightly activity sessions) – Highlights include the increased use of visiting dental services and flu vaccination campaign (see photo below with our Dr Gillian Eastgate).



Train-the-trainer on Good health and well-being

Miriam Taylor, Education Coordinator, has run three train-the-trainer sessions on the free, online kit Good Health & Wellbeing <http://www.ndsqlldprojects.net/good-health-and-wellbeing.html> for National Disability Services' clients in Redcliffe, Caboolture and Brisbane. QCIDD staff have also presented the kit in full-day sessions to direct support workers (see Prof. Nick Lennox and Carmel Blackburn below presenting to support workers).



Co-Presenter Profile—Meriel Stanger has been co-presenting to Oral Health and Dentistry students at the University of Queensland for over six years on dental health issues for people with disability, and has been involved in the Relationships and Sexuality Disability Network.

Meriel's story can be found in her two books, "Permission to Shine—The Gift" and "Shining On—The continuing journey of developing a meaningful life" which are available via mstanger@powerup.com.au

Recently, UQ Oral Health Therapist, Leah Hobbs, following a co-presentation with Meriel said: "Saw some students at the coffee shop today, one student who has always disliked health promotion came up to me and said her eyes have now been opened for preventing oral diseases instead of being restorative focus. My heart was singing! Our job here is done!"



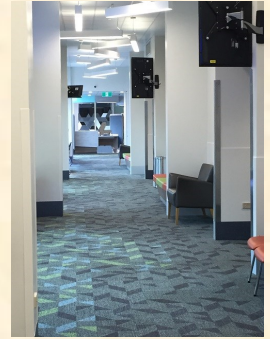
QCIDD CLINIC

As many of you may be aware our QCIDD clinic has moved to the Salmon Building (formerly Mater Children's Hospital) on Level 4 in the MYAHCB – Mater Young Adult Health Centre Brisbane.

Our new space is bright, roomy and a very nice space for our clinicians to consult in. The waiting room has more space for wheelchairs and to 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**.



Telepsychiatry Clinic (Skype Consultation)

QCIDD continues to run its telepsychiatry clinic on a Tuesday morning. This clinic uses Skype (or similar technology) to consult with people who live in rural or remote areas and cannot come to our clinic in Brisbane.

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.

Q: What is a Telepsychiatry clinic?

A: This is a clinic using the internet and a videoconferencing programme (e.g. Skype) to talk with people. The Psychiatrist (Dr Franklin) consults with the patient, their family and / or carers over the internet.

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).

Just let us know that you are interested in telepsychiatry. If 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 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 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.

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?

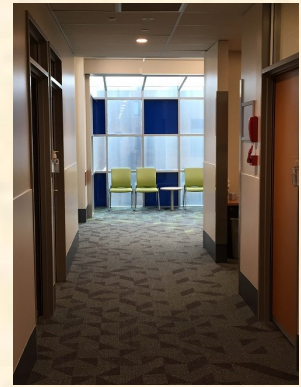
A: This service is free to the patient and is supported by the Mater Hospital.

QCIDD CLINIC UPDATE

QCIDD Clinic

The current waiting list times:

- Prof Lennox—6 months,
- Dr Gillian Eastgate—6 months,
- Dr Cathy Franklin—3-4 months.
- Dr Oreste Theodoratos—3-4 months
- Dr Margo Lane —4 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.

_

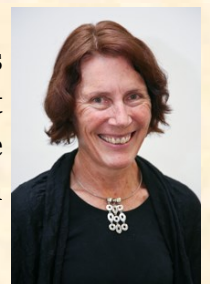
QCIDD Family Discussion Series 2015

25th March 2015 – The “CHAP” and commonly missed health problems

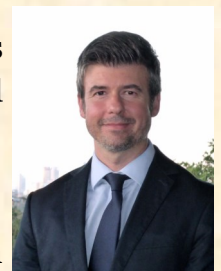
9th June 2015—Emotional Health and Medications: FAQs

The group discussions were attended by family members of adults with an intellectual or developmental disability. QCIDD clinicians aimed at increasing knowledge and awareness of health and mental health issues common to people with intellectual or developmental disability. This provided an opportunity for discussion and informal networking.

The “CHAP” and commonly missed health problems presentation included discussions on physical health problems and introduction to the Comprehensive Health Assessment Program (CHAP). This is a tool that patients, families and GP’s can use to improve people’s health care. Dr Gillian Eastgate followed up with a presentation on constipation and how best to manage and prevent it.



The Emotional Health and Medication: FAQs presentation by Dr Oreste Theodoratos discussed medications used for a person's emotional health, treatment options and clinical tips.



We intend to have another Family Discussion session later in the year. Part of our aim with this group is to set up a contact for families experiencing similar issues to be able to talk to one another.

What is the CHAP? - The Comprehensive Health Assessment Program (CHAP) is designed to help minimise the barriers to healthcare for people with intellectual disability by prompting health care and screening. Developed at The University of Queensland by Professor Nick Lennox, the program is used in Australia by various state governments, as well as the Endeavour Foundation (Qld) and other non-government organizations, and in other countries.

How the CHAP works - The CHAP is a tool designed to prompt a comprehensive health assessment for adults with intellectual disability. It helps doctors to make better diagnoses, provide appropriate treatment and ultimately promote overall better health. The CHAP tool is a two-part questionnaire requiring collaboration between the person with the intellectual disability, their supporter and their GP. The first part of the questionnaire creates a comprehensive health history and is completed by the parents, paid support staff and/or person with intellectual disability. The health history is then taken to the person's GP. Working with the person and their supporter, the GP fills in the second part of the questionnaire. Here, the GP is prompted to be aware of commonly missed, poorly managed or syndrome-specific health conditions and performs a review of the person's health. On completion of the GP's review, a health action plan should be agreed upon by the GP in collaboration with those involved in providing support or the person themselves.

Evidence behind the CHAP - The CHAP has been validated in several Australian studies. Its importance has been recognised by leading international researchers, for example according to Professor Eric Emerson, a respected researcher in the field of intellectual disability, the CHAP study contributes to the world literature the most conclusive evidence that health gain resulted from an intervention. These studies focused on adults with intellectual disability who had high to low support needs, and the results are explained in the following publications:

Lennox N, Bain C, Rey-Conde T, Purdie D, Bush R, Pandeya N. Effects of a comprehensive health assessment programme for Australian adults with intellectual disability: a cluster randomized trial. *Int J Epidemiol.* 2007 Feb;36(1):139-46.

Lennox N, Bain C, Rey-Conde T, Taylor M, Boyle FM, Purdie DM, et al. Cluster randomized-controlled trial of interventions to improve health for adults with intellectual disability who live in private dwellings *Journal of Applied Research in Intellectual Disabilities.* 2010;23(4):303-11.

CHAP updated annually— The CHAP is updated on an annual basis in line with current evidence and national and international guidelines. The version number corresponds to the year. Each CHAP is valid for only one year. One-third of the proceeds from the purchased CHAP licences goes to our Centre to fund more health advocacy and clinical work.

Why use the CHAP? Professor Nick Lennox explains the benefits:
https://www.youtube.com/watch?v=zQj2_H6QQ1A

CHAP and Medicare Australia - There are four Medicare Benefits Schedule items for health assessments based on the length of assessment (items 701, 703, 705 & 707). www.medicareaustralia.gov.au/

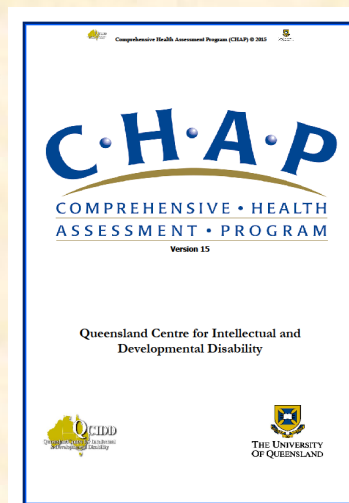
To obtain the CHAP, please contact:

Paul Stockwell, Contracts Manager, UniQuest Pty Limited

T: (61-7) 3365 7476 F: (61-7) 3365 4433

E: p.stockwell@uniquet.com.au

W: www.uniquet.com.au



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.



Oral Health Survey

Are you an adult with ASC interested in contributing to understanding of autism and oral health?



We would like to invite adults with ASC to take part in a new research study.

This project is investigating oral health, dental needs and barriers of adults with Autism Spectrum Conditions (ASC).

Very little is known about the oral health needs of adults with ASC. Through our work through the Cooperative Research Centre for Living with Autism (Autism CRC), we hope to work with adults to address current gaps in understanding and knowledge. Our aim for this study is to conduct a survey of adults about their oral health; dental needs and barriers. This survey study is very important for guiding future ASC services, and we anticipate it will take about 20-30 minutes of your time.

If you would like to take part in this study or find out more, please email Anna Urbanowicz at a.urbanowicz@uq.edu.au. Anna is a postdoctoral fellow at the Queensland Centre for Intellectual and Developmental Disability, and is working with the Autism CRC. If you email Anna, she will contact you to discuss the study further, provide you with the opportunity to ask questions, and outline the next step in this important study.

We look forward to working with you to contribute to better understanding of adults, autism and oral health.

Students at QCIDD

Imogen Page is a HLTH3001 student who has joined us at QCIDD to do her Bachelor of Health Sciences Placement. She is working with our Autism CRC PhD Student Cindy Nicollet to create some resources to add to those we have already created for the Autism CRC Connect Health Hub see <http://autismcrc.com.au/health-hub>.



These will include information on:

1. What a successful therapeutic relationship looks like

After reviewing the literature she is developing a fact sheet (Easy English) on what qualities make for a successful therapeutic relationship between an adult on the autism spectrum and a Psychologist. This will include some information in relation to communication and sensory concerns.

2. Your rights and responsibilities as a client

Stemming from the fact sheet on qualities that make a successful therapeutic relationship, she is aiming to develop a fact sheet in relation to the rights and responsibilities of the patient throughout this therapeutic relationship.

Imogen also hopes to develop a Flow chart on Mental Health Service access, detailing steps a patient needs to take in order to commence the process of going to see a Psychologist.

Rebecca Zale is a Bachelor of Health Sciences (Honours) (BHLthSc(Hons)) student also with us this year. Rebecca, like Imogen first came to QCIDD as a HLTH3001 student on placement and has returned to work on another Autism CRC project.

Adults on the spectrum are grossly underrepresented in the literature, despite the unique needs and comorbidities within this population. While there is an abundance of resources available for parents of children on the spectrum, once these children become independent adults, information and support is scarce. Aspects of independent living such as socializing, employment and autonomy in health are under-researched, particularly from the perspectives of the individuals. Rebecca's study aims to collect rich data capturing the perspectives of adults on the spectrum and their experiences with food and the barriers and enablers to enjoyable eating through qualitative measures. Using inclusive research practices, she hopes to empower individuals on the spectrum to express their views and identify areas of need.

Young people who had enrolled in a Pilot cooking class program also being conducted by QCIDD and the CRC were approached to participate in Rebecca's study before they started the cooking program. Spectrum Cooking Classes are being conducted by chef and teacher, Dominique Rizzo, who has designed cooking classes to suit the needs and preferences of her participants on the autism spectrum.

Rebecca's study involves two rounds of semi-structured interviews along with photovoice, with 5 adults on the autism spectrum. Photovoice is a qualitative tool that enables recording and reflection of environmental and social components through photographs taken by the participants themselves. She has completed the first round of interviews and also introduced the participants to photovoice process in which they will be asked to take pictures of everyday activities surrounding food such as cooking and mealtimes. It is anticipated that the inclusion of photovoice will assist participants with memory recall and provide the researchers with material for the second phase of interviews. It is also expected that photovoice will help engage participants who experience challenges with verbal communication and social interactions and will facilitate more in-depth discussions with the researcher.

She has completed the second round of interviews and during interview, participants are being given the opportunity to draw on photographic evidence they have collected and describe their experiences through the images. The results will undergo a thematic analysis to identify themes within the data.

It is hoped that the results will contribute to the small existing literature surrounding perspectives of adults on the spectrum and their experiences with food and mealtimes.





RETT
Syndrome
Association
of Australia



GEELONG

IS PROUD TO PRESENT

the first ever Australian national RETT conference.

“The Rett Syndrome Journey: Pathways to Follow”

19th, 20th and 21st November 2015

at the Novotel Geelong

‘Pathways to Follow’ on the journey with Rett syndrome will be explored in such areas as communication, health, therapies, education, equipment, caring for the carer, Commonwealth government, trusts, siblings, adulthood, family and equipment, to name just a few. Exhibits will also be presented which relate to a number of these topics. Starting at 4pm on the 19th with the Annual General Meeting (AGM) of the RSAA

WORLD RENOWN GUEST SPEAKERS:

Kathy Hunter (USA) – Author of ‘The Rett Syndrome Handbook’;

Meir Lotan (Israel) – Physiotherapist with 20 yrs exp in therapeutic intervention in Rett syndrome;

Mary-Louise Bertram (Australia) – Local expert in the areas of communication, sensory processing, and literacy support.

Sally Ann Garrett (Ireland) – Specialist RETT Speech and Language Therapist (SLT)

Associate Professor Helen Leonard (Australia) – Established the Australian Rett Syndrome Study, Author/Co-author of 100 articles on Rett

Jenny Downs (Australia) – Focus on function, nutrition, spine;

Professor John Christodoulou (Australia) – Director of the New South Wales Centre for Rett Syndrome Research.

Early bird \$90 (for RSAA member in 2015/16) \$120 (non member) per person attending the conference. Flat rate of \$140 if you register after 31st Aug. Includes meals and snacks throughout the day as well as food provided at the Thursday night Cocktail party and Friday night dinner.



TRIBUTE

During the dinner on Friday evening, a tribute will be held in honour of the children and adults with Rett syndrome, their families and friends. Therefore, we are asking for a high resolution photo (in jpeg format) or two of your Rett child/ adult to display in the slideshow. If interested, please also include her/his name, age and suburb/town or city, with the photo (s) and send to the RSAA Secretary **Caroline Fitzpatrick** at cdfitz73@gmail.com

Contacts for the event:

Caroline Fitzpatrick 0427 422 788, Bill Callaghan 0418 561 796, Claude Buda 0411 089 156



There will be a Crèche available at the conference for both our Rett children/ adults with professional carers and their siblings with activities to keep them entertained.

For more detailed info visit www.rettaustralia.com and click on the news tab

QCIDD links to view at your leisure

- 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
- 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/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>