QCIDD

QueenslandCentre for Intellectual & Developmental Disability

Located at
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THE UNIVERSITY
OF QUEENSLAND

July-December 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

I wish you and your family an enjoyable festive season. The second half of 2016 has been very busy at QCIDD. QCIDD staff continue to deliver clinical services which are now better integrated into the Mater Health Service due to the dedicated work of many people but especially Julie Gibson, Cathy Franklin, Dell Hele and Ildiko Putnoki. The clinical service is delivered by phone, telepsychiatry or face-to-face and remains very highly valued by all those involved. QCIDD will continue to push for more clinical services as the waiting times remain unacceptably long. However, one of the real successes has been the training of young psychiatrists who have worked with us over the last few years. Dr Cathy Franklin successfully gained federal funding for these positions and supports the trainees to gain a higher level of expertise. They then move to new roles as Consultant Psychiatrists with an interest and expertise in the mental health of people with intellectual and developmental disability and work in the public and private sector. This is an important albeit gradual change in the amount and quality of expertise available to people with intellectual and developmental disability, and mental health problems. We have had and continue to have really excellent trainee psychiatrists work with us who are now available, well trained and keen to provide high quality mental health care.

We continue to deliver research outputs with record levels of presentations, publications and successful grant applications in the second half of 2016. I am particularly delighted with Dr Cathy Franklin's successful application to gain a BICARE grant for "Investigation of Catatonia and Acute Regression in Down Syndrome". A truly important piece of research which seeks to understand this distressing change experienced by some people with Down syndrome. Anna Urbanowicz and I also gained funding to find ways to improve the accessibility of the Autism CRC health hub for people with intellectual disability and autism, and the development of 'health pathways' for children, adolescents and adults on the autism spectrum www.autismcrc.org.au/healthhub. In addition, Lyn McPherson and Anna Urbanowicz have worked with others to gain funding for the development of a 'health passport' for children, adolescents and adults with disability for use in the hospital setting. Finally, we just found out that with Prof Julian Trollor and his exceptional team at UNSW we successfully gained funding from the highly competitive project grant scheme of the NHMRC to look at the health status of people with intellectual disability during the period of the roll-out of the NDIS in NSW.

In August 2016, the IASSID world congress was held in Melbourne and allowed us to present our work and also link with many other researchers across the globe; including some international colleagues who visited us on their way to and from the conference.

Finally although you have heard us crow about it before the world's first online courses on health and people with intellectual disability, called the Able X series has enrolled more than 7000 students from 135 countries over six months with many thousands completing the courses! Now relaunched with new URLs (see below) these free courses are there for you to use, freely download the videos and share with staff, family members and people with intellectual disability. You can hear the comments and insights from participants across the globe towards the end of this newsletter. They make interesting reading and highlight the common challenges we all face as we aspire to improve the physical and mental health and healthcare of people with intellectual and developmental disability.

Nick Lennox

The QCIDD staff and students would like to wish you a happy holiday season and sincerely thank you for your continued support and contribution throughout the year. We look forward to working with you again next year.

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 having sufficient space for wheelchairs and accommodate a greater number of patients, families and carers.

QCIDD welcomed Dr Matthew Sellen at the beginning of August 2016 when he commenced as Psychiatry Registrar in a Specialist Training Position Post at QCIDD. Having a Registrar at QCIDD has meant that many more people can be seen in our QCIDD clinic and has reduced the length of our waiting times considerably.

We say goodbye to Dr Margo Lane, GP and Dr Oreste Theodoratos, Consultant Psychiatrist and both will be sadly missed by the clinical team and our patients. Dr Theodoratos will still be at the Mater in private practice.

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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QCIDD CLINIC UPDATE

The current waiting list times are:

- Prof Lennox (Director, General Practitioner)—12 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.

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 / 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?

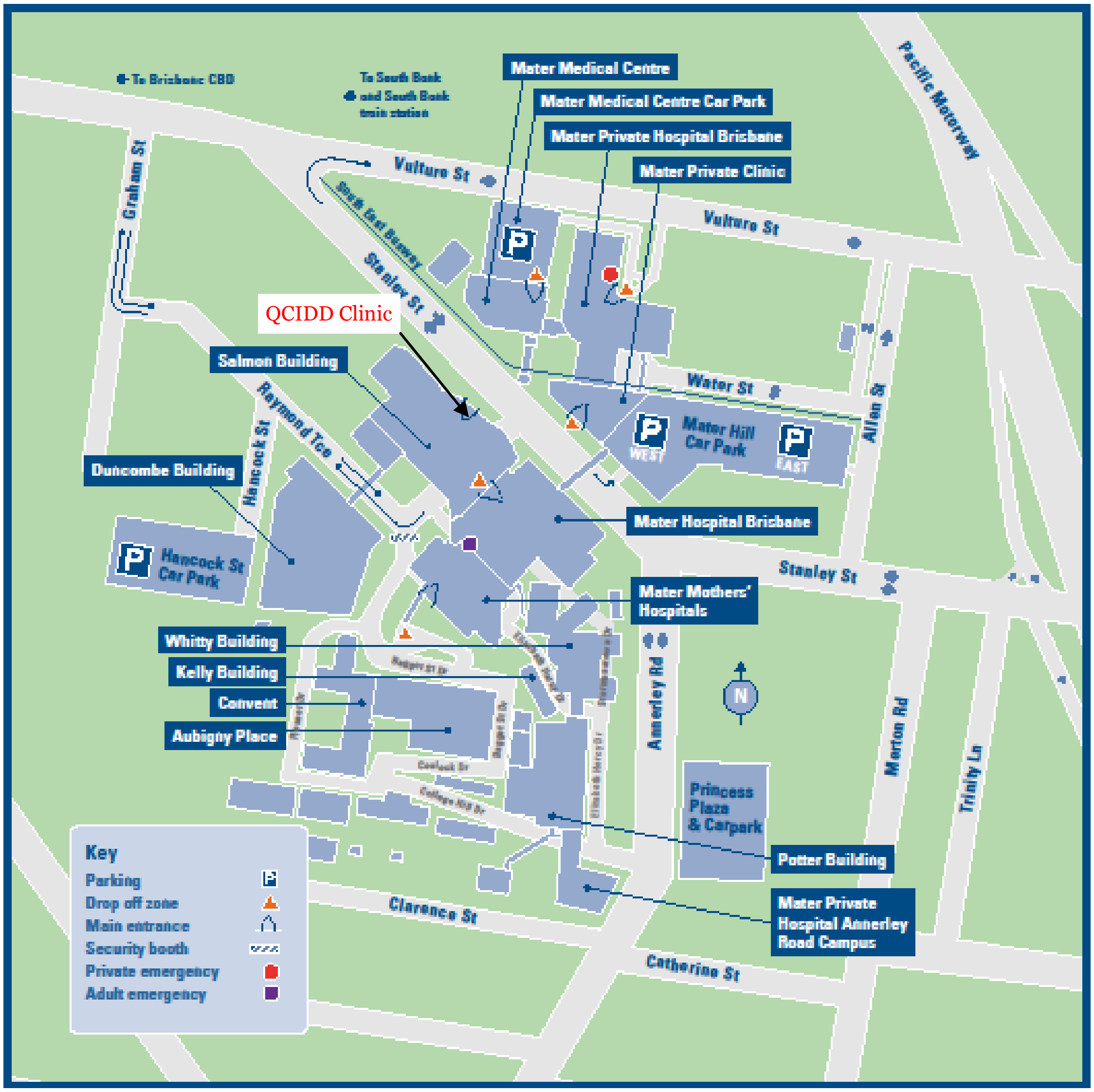
A: People who live in Brisbane or parts of the Gold or Sunshine Coast are not eligible for this service currently. If unsure, please ask us and we will find out for you.

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.

Mater
Exceptional People. Exceptional Care.

QCIDD Research

Lyn McPherson
Research Coordinator

Grants:

Dr Cathy Franklin was successful in obtaining a BICARE grant for "Investigation of Catatonia and Acute Regression in Down Syndrome" study over a 3 years period. Cathy is the Principal Researcher for this study which is conducted in collaboration with a number of eminent researchers from the Qld Brain Institute at UQ. The study will use MRI imaging, amyloid PET scans, genomic sequencing, blood inflammatory biomarkers and stem cell research to investigate the cause of catatonia and acute regression in young people with Down Syndrome.

Prof Nick Lennox and Anna Urbanowicz were successful in obtaining funding from Autism CRC in the 2016 grant round for utilisation and innovation projects. The project will involve the utilisation of health hub resources by adults on the spectrum with intellectual disability and their caregivers. They are also team members of two other successful projects for designing a 'health passport' for children, adolescents and adults with disability for use in the hospital setting and the development of 'health pathways' for children, adolescents and adults on the autism spectrum. www.autismcrc.org.au/healthhub

In other recent news, Prof Lennox is a chief investigator on a project led by Prof Julian Trollor from the University of New South Wales that has been successful in receiving funding from the National Health and Medical Research Council for 2017. This project will link administrative and health data from multiple sources to examine the health and health service use of people with intellectual disability in NSW and compare these results with those of a matched general population group. It will also examine the impact of the NDIS roll-out on health service use in NSW and hopefully directly influence strategies directed at improving the health of people with intellectual disability.

QCIDD Staff Attend IASSIDD

The 15th World Congress of the International Association for the Scientific Study of Intellectual and Developmental Disabilities (IASSIDD) was held in Melbourne 14-19 August 2016. The fact that this was held in Australia meant that more QCIDD staff than normally are able could take the opportunity to attend this event, which brings together the most respected international researchers in the field. Nick Lennox, Cathy Franklin, Julie Gibson, Anna Urbanowicz, Lyn McPherson, Cindy Nicollet and Katie Brooker all packed their overcoats and headed south. During the six days, they attended presentations, poster sessions, roundtables and workshops, learning much about the current state of research in their areas of interest. Nick, Anna, Cindy and Katie gave oral presentations and presented posters during the week

Presentations

Nick Lennox
  Improving health advocacy and health outcomes in adolescents with intellectual disabilities.
  The health of adolescents with intellectual disabilities
  AbleX – Intellectual disability healthcare around the world: a poster.

Cindy Nicollet
  A systematic review and meta-analysis of psychological interventions for adolescents and adults on the autism spectrum with anxiety
  The experience of anxiety in adults with autism: A qualitative analysis.
  An anxiety intervention program for adults on the autism spectrum, a pilot study: a poster.

Katie Brooker
  The relationship between social support and physical activity for adults with intellectual disabilities.
  Applying inclusive qualitative research practices with adults with intellectual disabilities: some reflection: a poster.

Anna Urbanowicz
  The development of new evidence-based resources for health professionals who work with adults on the autism spectrum
  Choice making in Rett syndrome: a descriptive study using video data.
  A exploration of the use of eye gaze and gestures in females with Rett syndrome
  The oral health and dental needs of adults on the autism spectrum: a poster.

Awards for Our Director

Photo courtesy of IASSIDD, photographer Geoffrey Pfitzer, Travel Design

It is at the International Congress that IASSIDD recognise outstanding contributions in the field of intellectual and developmental disabilities. Professor Lennox was awarded the status of **IASSID Fellow** and was also the recipient of the **Distinguished Achievement Award (Research)** which is given in recognition of formulations and investigations which have contributed significantly to the sciences; for either a major single contribution or a sustained and important contribution over a lifetime. QCIDD staff cheered loudly as Nick took to the stage to receive this award from Vianne Timmons, the president of IASSIDD.

International Rett Syndrome Conference RTT 50.1

Photo left to right: Helena Wandin, Theresa Bartolotta, Anna Urbanowicz, Sally-Ann Garrett & Gill Townend

This September post-doctoral research fellow, Anna Urbanowicz, attended the International Rett Syndrome Conference held in Vienna, Austria. The conference coincided with the 50th anniversary of Andreas Rett's first publication on Rett syndrome and provided an opportunity for conference attendees to reflect on the last 50 years of research and to look forward to the future of research in Rett syndrome. Anna presented on her PhD work exploring the communication abilities of girls and women with Rett syndrome. Anna together with colleagues from across the globe, presented a poster outlining the development of clinical guidelines for the management of communication in individuals with Rett syndrome. The guidelines will provide much needed information and direction for professionals and caregivers in the management of communication and will ensure consistent information is provided to families around the world. If you are interested in learning more about the clinical guidelines project please contact Anna on 07 3163 1983 or a.urbanowicz@uq.edu.au

Visitors to QCIDD

On her way to the International Association for the Scientific Study of Intellectual and Developmental Disabilities (IASSIDD) 15th World Congress in Melbourne **Esther Bakker-van Gijssel**, an experienced specialist physician in the health care of people with intellectual disability from the Netherlands came to visit QCIDD. She is doing her PhD on health maintenance/health assessments in the Dutch system and was keen to learn as much as possible as to how a tool like the CHAP could be embedded into primary care.

Also on her way to IASSID, **Dr Deborah Chinn**, a clinical psychologist and researcher based at King's College London stopped off in Brisbane. She gave a short presentation at QCIDD on her project looking at the health communication of people with intellectual disabilities, which included video-recordings of GP health checks with people with intellectual disabilities to look in detail at communicative strategies used by all participants that contribute to patient involvement and decision-making.

We were also asked to host **a delegation sponsored by American Association on Intellectual and Developmental Disabilities (AAIDD)** led by Margaret Nygren EdD, Executive Director & CEO of AAIDD.

The goal of the delegation was to research the supports provided for people with intellectual and developmental disabilities in Australia. As Brisbane was their first stop in Australia, QCIDD organised a workshop for the visitors to give them a brief overview of the Australian health system and intellectual disability from a Queensland perspective. Speakers included our own Prof Nick Lennox and Dr Cathy Franklin who spoke on physical and mental health services respectively.

Ms Jodie Griffiths-Cook, who recently resigned as Queensland Public Advocate to move to Canberra, spoke on Advocacy & Guardianship in Australia and Prof Leslie Chenoweth presented on Intellectual and Developmental Disability Policy and Practice in Australia.

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.

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.

Comprehensive Health Assessment Program (CHAP) for Adults

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. 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 autism.adulthealth@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 research study which aims to improve our understanding of the health and wellbeing of autistic adults and their carers in Australia. 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 Dr Kitty Foley or Ms Jane Hwang on (02) 9385 0620 or autismcrc@unsw.edu.au or go to this link:
https://autismcrc.au1.qualtrics.com/jfe/form/SV_1UoHxlKX4M0WRo1

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) .

QCIDD Education

Miriam Taylor
Education Coordinator

Since September 2016, the QCIDD educators have done a great deal of work!

Professor Nick Lennox presented to the ASID New Zealand annual conference as a keynote address. Dr Cathy Franklin presented to psychiatry trainees. Meanwhile, Miriam has been co-presenting with long-time tutor, Peter McMeekin, on disadvantaged patients to the GP Rotation in Medicine. Miriam presented to Centacare managers and then to Metro North Hospitals and Health Service about the mooc.

Miriam was involved with a powerful coalition of lawyers, advocates and disability service providers to present Queensland's first state forum on examining the limitations to consensual sexual expression for persons with an impairment of the mind. *The Rights Denied Forum* was held on 14th September and was well attended with such speakers as Michelle O'Flynn from QAI and Benedict Coyne from Australian Lawyers for Human Rights. This forum followed the *ABC Australian Story Tough Love* which examined the sexual rights of a couple with Down syndrome (http://www.abc.net.au/austory/content/2016/s4539439.htm), into which Miriam had a great deal of editorial input with ABC Producer Kirstin Murray.

The ABLE X Series has been reviewed and we are proud to have had more than 7000 students go through from 135 countries over six months! The student comments are so positive and we are very pleased to announce the re-release of all three courses. You can sign on here:

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

We will continue providing high quality educational activities and presentations, as we work to embed the ABLE XSeries in university courses around Australia and globally.

Here are some of the great insights from students throughout the courses over 2016:

PERU

In Peru there are many barriers to people with mental disabilities. The law does not protect them. Real inclusive education is not practiced, because teachers are not trained to meet the needs of these children. Other children may reject them and they are not given the tools to deal with the difficulties of life. When they go to work life, most companies are unwilling to hire them or employers exploit them. People with intellectual disability get support from their families. Some manage to develop in arts, sports. Others receive occupational therapy and then manage in simple occupations. But it´s not easy, medical treatment is expensive and get specialized therapy too.

UK

I have just watched the video Through my Eyes. It unfortunately isn't an unfamiliar story. Someone who has support needs but isn't receiving what they need and ends up being extremely vulnerable living on the streets. Great to see how happy he is and how proud he is of all the things he does now. In England I have supported a vast number of people with disabilities, fortunately none of the have gone through the difficulties of living on the street but some have had neglectful back grounds which can lead to further difficulties for them.

GREECE

Bullying exists in my country (Greece) also for people with mental disabilities. Now, conditions have changed for people with disabilities. Their unions and associations help to preserve their human rights. But, bullying still exists. The state has to take measures in order to prevent bullying and to teach other children respect disabled people.

CANADA

That's interesting to hear. My uncle (who's is about 55 now) has a learning disability. When he was a child growing up in Canada (hearing this from my dad), school wasn't that great. They were only starting to become aware of different types of learning disabilities and as such he didn't have many options for schooling. Fast forward to today, where there are many programs available, he has had a job for 25+ years in a library through a government supported program where he has learned many skills and more importantly, made tons of friends in a place he enjoys going to everyday.

CROATIA

I am from Croatia. I am psychologist and work primarily with children. the biggest problem in my country that after the diagnoses, and in early ages after seeing that the child needs additional therapy I don't have where to send those children! There are too little number of places and experts that are involved with people and children with disabilities!

NIGERIA

People with Intellectual disabilities here in Nigeria honestly have little or no chance of living a normal life. The only support most get are from their families alone. Having a family member with disability most times puts a stigma on the family, and if the said family isn't buoyant enough to cater for the needs of the disabled person, they abandon him/her, and they in turn resort to begging as a means of survival. I have heard of a private boarding school for intellectually disabled kids where they learn crafts like pottery, basket-making etc; but after they are older and leaves the school where do they head to? Who employs them? I am yet to see an intellectually disabled person in a paid employment here.

USA

USA - Alaska - what I have noticed too is that nobody (yet) has spoken much about the physical barriers where someone lives. I live in Alaska, and to live here it means dealing with snow and ice, boats, planes, and other forms of transportation to around, and many places outside of the big cities are not ADA accessible yet because we are about 30 years behind the rest of the country. Regardless of the services you may have available, if you are wheelchair bound, for example, you may not be able to leave your house because of the snow.

IRAN

Iran - I assume this question is not something new to people who are surfing about the lives of people with intellectual disability. I am talking to parents having children with developmental disabilities for the past two years. I talked to some 53 parents. I noticed every parents are in search of medical cure and doing medical shopping for their children. Nobody shared a story where medical professionals has come up with a cure for their child's disability. Let me admit that I am not worshipper of Social Model of disability.

INDIA

I am from India. I know a lot of kids with disability. They face a lot of things, to start with, many are denied education. The right to live peacefully in their own community. The lack of awareness in the people is creating a lot of barrier for the disabled which has a great influence on the family as well. The society plays a huge role in creating a barrier for such people and is sad that the government is not taking a serious look into it

MEXICO

Even when, in my city (and many places in my country) there are hospitals and centers for people with intellectual and physical disability, I feel that the problem resides, mainly, in society. I'm speaking, obviously, from what I've seen firsthand: people making fun of the way persons with disabilities speak or move, refusing to give them jobs, thinning they should be confined to a bed, etc. Mexican culture values hard work a lot so, once they label you as "unable" of doing something they can do, you cease to exist to them. There's another side of the coin, of course. For example, here in Mexicali is a baseball team than accepts kids with all kinds of disabilities and that really helps them build confidence.

CHINA

China is a large developing country. There is a great difference between different places within the country. Generally, China has established the law and built facilities for those has disability or difficulties. The extent varies. In the big cities, the provisions is better and international. However, in the remote towns and country side, the situation is not so good, though not too worst. We still working hard to build a better life for all.

KENYA

People with Intellectual Disability, both children and adults are still regarded with an attitude in my Country Kenya. The barriers here is huge due to lack of amenities, equipment, schools, care givers, and health care. Society at large is yet to be receptive of them some families with people with Intellectual disabilities shy away; thus isolating them and treating them differently from the normal being. The stigma and discrimination is a major concern.

JORDAN

In my community parent-child relationship is so important and respected so it's not usual to find a disabled child alone by himself without help but the problem in my country is the low awareness of people with disabilities unfortunately they are considered as a non-productive part of the community. This leads to negligence of their role and their rights. There are no enough centers for them and they usually get enough learning or jobs. But they get some health care and they participate in some activities like special need sport competitions.

UAE - Here in Dubai where I'm working, the government, families involved, some organizations and volunteers are paying much attention to children with intellectual disabilities. In fact, there are lots of Schools and Centres here for those mentally- challenged children. Some activities were held indoors and outdoors, for them to get recognized and helped them live and act freely as some normal individuals.. And in some private families, they are visiting clinics monthly or as per required by their private doctors, and in house, it calls for a one-on-one attention with their healthcare providers. Too severe such situations, so every people involved are giving more time as to provide proper healthcare and education to those children with special needs.

AUSTRALIA

All people with disability are different and should be seen as such however this is not always the case. There is a stigma and a fear around disability for many non-disabled people so people with disability may live in the community, but too few are actually 'part' of it they seem to 'sit on the margins and do not fully participate in it. Many lonely lives of exclusion and isolation; some people have limited voice so are not heard and their options are not valued. Adults with intellectual disability are often not treated as adults and have had limited access to education and careers and so have limited opportunity to participate in and be part of their communities. They are often not offered choice and as such face socially, culturally and politically isolation. There are still many myths about people with intellectual disability and this contributes to the challenges they face. Misconceptions such as people will die young, people with Down Syndrome are always happy, people with intellectual disability can never live independent lives, people with autism are incapable of feeling, people with intellectual disability cannot have relationships (are not sexual beings) or children, I could continue but I think you get the picture – what I am getting at is these misconceptions create barriers for people with disability and can hold them back from living fulfilling lives.

ZIMBABWE

It is very difficult for people with intellectual disabilities to access health services since most of the time the resources are scarce and only those who are able bodied would jump ahead leaving other who are not physically active at risk of not getting services.

TURKEY

I am working in one of the best centres in Istanbul, and we do our bests for our students. Our students have different disabilities. They are the lucky ones. My concern is the other children in other cities, that people do not care about people with disabilities much. It cannot be solved by just us. It needs the governments full support on subjects like that. So, I wonder what kind of opportunities disabled people have in your countries. Thanks in advance for your answers!

BRAZIL

As a sister of two intellectually disabled people, I can understand quite well some of the challenges that special needs people and their families might face. Although one of them is much more dependent on us to do the daily activities and has difficulties to express himself, I believe that it is much more challenging to offer healthy and happy life conditions for the other one, who can do everything by himself but has a slight mental retardation. In Brazilian cities, there are quite a few schools for special needs students, and one of my brothers studies in one of them. However, for the other one (who is not mentally delayed enough to fit in a school like that nor academically capable to finish high school), there are not many options. Finding a job if you have an intellectual disability is not an easy task, and I think the government should build mechanisms to provide better access to work for people like my brother.

PANAMA

Most discussion about people with disability revolves around laws that grant basic human rights and the obligation to build some special infrastructure to help with urban mobility (mostly in the capital city). Nevertheless, social inclusion remains absent. Most social activities are promoted for persons with no intellectual disability so it is hard to find spaces where both segments can interact and integrate.

THE NETHERLANDS

There are health institutions where the intellectually disabled receive care and coaching. There are 24-hours settings, to house patients who cannot live by themselves and whose families are not able to provide the care they need and deserve. In these settings there is always a care provider available. An option for intellectually disabled who don't need constant care and are fairly independent (or live with family/have family over regularly), is to have a care provider come to their house every day for a few hours or even a few hours a week, to help them and coach them where needed. Schools try to give intellectually disabled students the education they need, however in the last few years more strain is being put on 'regular teachers' as opposed to providing special education by trained teachers. (Due to financial cuts) There are a lot of 'social workplaces' where intellectually disabled people are given a chance to work, to feel productive and to add something meaningful to society.

THE PHILIPPINES

Here in the Philippines, the National Council on Disability Affairs is the national agency mandated to formulate policies and coordinate the activities of all agencies, whether public or private, concerning disability issues and concerns. It is the lead agency task to steer the course of program development for persons with disability. It is establish to formulate policies on disability prevention and rehabilitation for the welfare of persons with disability. It also formulate research and development policies for health and education of persons with disabilities. IN the Philippines, there are institutions that help people with disability to have access with adequate health care programs for disabled person especially for the poor. There are institutions that gives free health care access like the National Mental Institute. There are also institutions which gives free intervention, therapies and consultation with children with autism, global developmental delays and speech delays.

ITALY

In my country there are various specialized institutions for people with disabilities. Are personal cooperative specialized in helping these people. Allow to integrate into society with jobs, create tools for theme and work on integration. Sometimes the only barrier is that we create ourselves.

NEW ZEALAND

After hearing Lal's story, I thought about my sister and the support she has received to establish herself as a valued member of the community. My sister has Down's syndrome and is currently the owner-operator of a cookie business, in which she bakes and delivers cookies to local businesses to sell for $1. As well as the physical task of baking cookies and following the recipe instructions, she also receives the social stimulation of visiting local businesses and receiving positive feedback on cookie sales. Both of these outcomes have dramatically improved her quality of life and given her a sense of purpose. Does anyone else have similar stories about people with intellectual disabilities who have become entrepreneurs?

PARAGUAY

I'm a dentistry student from Paraguay, every day in my school comes people with intellectual disability that are looking for dental attention, and every day I can see how some doctors ignore them just because their conditions justifying that they need more time for them, so basically they say that they are a waste of their time. I always have discussions with them because I don't think that they are a waste of time, I always tell to them that everyone it has to be respected in the same way and they have the same rights as others.

CZECH REPUBLIC

Every month everyone at the age 18 and older has to pay health insurance, but otherwise the basic health care is for free - for example if you have a flu, visit a dentist, break a leg, have a heart attack... the medical care is for free. Sure, you have to pay for the medicine, special props like a wheelchair or new teeth. But I guess for major part of the population the system works fine. About people with intellectual disability, I suppose, it depends on the depth of the disability on the complications, what is needed and what is wanted and required by the family. Either way I think it must be very challenging for the family and for the disabled person, mentally, financially, socially. But I must say what I see around, the situation is improving, kids can be included, there are new range of professionals, new approaches, new methods.

USA

I live in the North Eastern part of the Unites States and I can say I have witnessed the inequality of health care among those that have an intellectual disability. Often doctors do not listen to their complaints of pain or other maladies. It is of great importance that staff persons advocate for the people they support.

COLOMBIA

In my country the persons with disability have big troubles to access to good health care institutions in the public way. Is very difficult for this families that have economic troubles and doesn't have the resources to pay in a private way the institutions that provide health care services.

SIERRA LEONE

In Sierra Leone, people with mental illness of different kind are housed in one place irrespective of age. As the aged with intellectual disability needs their relatives around them they need to be stationed in one place with their families and friends.

LEBANON

Communication is the best way - by provoking the maximum communication with the child in question, his family, and his community, so as to find the most integrated and informed way of helping him out.

ROMANIA

In my country (Romania) the most encountered aspects that need special attention and care for people with intellectual disabilities that are aging are: -physical problems that lead to decrease movement and therefore a poor exercise life, -dental care because of the lack of dentists that are trained or willing to spend time and treat a person with intellectual disability, -the lack of good healthcare system facilities that takes good care of people with disabilities in case of falls, -the lack of training/educational programs for families with intellectual disabilities that are reachable to everyone, -in general, support for the person with disabilities should be more accessible, less expensive, more flexible, and clinicians should be trained to work with people with intellectual disabilities.

IRAN

Depression and bi polar disorder are prevailing mental health challenges in my country. There is no doubt that a complex interplay of genetic, biological, personality and environmental factors causes mental illnesses. However, based on my observation, due to the financial difficulties stemmed from systematic corruption and international sanctions, any glimmers of hope has gradually gone in Iran and people , in general, cannot see any clear future. Unfortunately, due to economic costs of mental illness, affordable mental health care is not accessible for many people in need of mental care.

AUSTRALIA

In Australia, there are very insufficient mental health resources for the identified need, much less those who have not been clearly diagnosed! Even when we have concerns as a health professional particularly for children there are very few effective practitioners, few places in programs, and difficulty getting appointments even if you can find someone. For people with ID it's just as bad if not worse. And I live close to one of our largest cities. In rural areas you have no hope.

UKRAINE

The mental health services in my country is quite poor as there are inadequate mental health practitioners and the deplorable state of the mental health institution is quite alarming. I have not really come across people in my circle with mental problems, it's just that the issue of poor mental health in my circle of family and friends has to do with bad education.

THE PHILIPPINES

As a graduate of BS Psychology and having worked in the field of helping professionals, I have first-hand experiences of the stigma the society has regarding mental health. People do not often go to a Psychologist or a Psychiatrist to get diagnosed because they are afraid to be termed as "crazy". This is very alarming especially since mental health is just as important as maintaining a physically healthy body.

JUST BECAUSE THEY CAN'T TALK, IT DOESN'T MEAN THEY CAN'T COMMUNICATE

Each patient should be treated as an individual. I think it's important to remember that just because a person can't communicate verbally, it doesn't mean that they can't communicate at all. Using pictures/ drawings and speaking to care givers can give vital information about the patient's difficulties.

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
- ASK Diary (Advocacy Skills Kit Diary) https://itunes.apple.com/au/app/ask-diary-advocacy-skills/id1095955087?mt=8
- ABLE101x Through my Eyes—Intellectual Disability Healthcare around the World— https://www.edx.org/course/through-eyes-intellectual-disability-uqx-able101x-0
- 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-0
- ABLE301x Able-Minded—Mental Health and People with Intellectual Disability— https://www.edx.org/course/able-minded-mental-health-people-uqx-able301x-0
- QCIDD's YouTube channel— https://www.youtube.com/channel/UChCUpCHdvnHqAf8SBOuV_tA
- 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— 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.uniquest.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
- 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/