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July–September 2014

Our aim is to improve the health and wellbeing of adults with intellectual and developmental disability in Queensland, through multi-disciplinary research, education and clinical practice.

Directors letter

Welcome to our newsletter. We have been very busy during 2014. There is so much exciting activities we are generating it is easy to lose track of the core work of our clinical service which this year has been augmented by the centre gaining funding for a advanced trainee in Psychiatry to work with us for a year.

Dr Cathy Franklin our consultant psychiatrist, wrote and drove this successful application. Currently Dr Oreste Theodoratos is working with us doing clinical work and starting research based on one of our recent randomised controlled trial of the Ask diary and CHAP health check tool. He has been a great addition to the team and has at least in the short term increased the services we can provide.

As you read through the newsletter you will see we have successfully run a conference called *Health and Autism Across The Lifespan*, had the QCIDD conceived *Walk and talk* program implemented across Queensland by Endeavour Foundation. We have also performed many presentations and had one of our key paid presenters win an award for his work.

Another world first for QCIDD is the development of a series of Massive Online Open access Course on health and intellectual disability. We hope to reach wide and far to improve the physical and mental health care of people with intellectual disabilities across Queensland, Australia and the globe. The series of three MOOCs, called an X Series, will be produced over the next 2-3 years and will be universally and freely available. The Edx platform <u>www.edx.org</u> is a collaboration between Harvard University, MIT and 34 universities and offer an extra-ordinary array of course which are open to all.

Finally we have been short listed for the Australian Innovation Award for the App development of the Ask diary. We have worked and tested the use of this Advocacy Skills Kit or ASK diary for the last 14 years. The research says it empowers people with intellectual disability so they go to the GP/ Family Doctor more often on their own and are more likely to speak up and communicate with their GP. We joined with an App developer and are currently Beta testing the App.

You can vote for the App and highlight the need to empower people with intellectual disability through use of the App. Just go to:

http://www.theaustralian.com.au/innovationchallenge/competition/innovators-find-new-ways-to-fight-deadlydiseases/story-fnj8dpqq-1227094107128

Hope you enjoy the newsletter. Nick Lennox



is here!

QCIDD CLINIC UPDATE

Our waiting list times to see our Psychiatrist Dr Cathy Franklin has improved as we have a Psychiatric Registrar attending our clinic. Please see below for our current waiting list times:

- Prof Nick Lennox 4 months,
- Dr Margo Lane 8 months,
- Dr Gillian Eastgate 5 months,
- Dr Cathy Franklin 5 months,
- Dr Oreste Theodoratos 5-6 months.

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

QCIDD Activities



AADDM—QCIDD Conference 2014

Health and Autism Across the Lifespan

Friday 22 August 2014

http://aaddmgciddconference2014.wordpress.com/

The joint AADDM (Australian Association of Developmental Disability Medicine) -QCIDD (Qld Centre for Intellectual and Developmental Disability) conference was held on 21-22 August 2014 at the Mater Hospital in Brisbane. The theme was 'Autism across the Lifespan', with a focus on issues of relevance to medical professionals.

Associate Professor Kate Sofronoff spoke at a pre-conference half-day workshop that focused on the evidence base for three of the interventions and programs currently available for children and adolescents with autism. This included the Secret Agent Society, which targets social skills in 8-12 year olds using a computer game-based group program. The computer game seems very well-designed and has amazing graphics courtesy of Disney Pixar! There are further studies involving its application as part of the Autism CRC (Cooperative Research Centre).

The conference day itself displayed some weather apparently imported from the southern states. Despite the dampness, it was an energetic day, with numerous interesting presentations. The conference was opened and led by Professor Nick Lennox and officially opened by Sister Angela Mary Doyle. The keynote speaker was Dr. James Morton, the founder of AEIOU early intervention center's for young children with autism. James is also a hematologist and has a son with autism, whose own challenges prompted him to establish AEIOU, which now has center's across Queensland and in Adelaide.

The conference day moved through the life span, beginning in childhood, with excellent speakers including Dr Mike Gattas. A clinical geneticist, Mike reminded us of the importance and relevance of microarrays in people with autism and updated us about next generation sequencing technology. The school years section included a fascinating presentation by Charmaine Driver, principal at Darling Point Special School, who continues to use applied behavioural analysis methods to promote positive behaviors in her students and staff! A/Prof Kate Sofronoff gave a briefer presentation on social skills programs in autism and Dr Jacqui Small reminded us of the importance of thorough health assessments.

The afternoon moved into adulthood and Professor Torbjorn Falkmer from Curtin University spoke of his research (which is also part of the Autism CRC) into helping adults with autism gain employment. Following on, there was a panel session where Prof Lennox provided the panel with a hypothetical and guided discussion. The panel consisted of Dr Michelle Garnett (Clinical Psychologist), Mr Michael Keates (Behavioural Psychologist), Dr Aline Smith (G.P.) and myself. I discovered both the advantages and disadvantages of being part of a panel (less preparation but no control!) but did my best to counter the claim that "Psychiatrists are just psychopharmacologists!".

The day closed with a presentation on autism and growing older, by Associate Professor Julian Trollor (Psychiatrist) and then Dr Seeta Durvusala (G.P.). This was also an opportunity to reflect on what successful and healthy ageing looked like and how ageing affects people with autism.

I enjoyed the day, which provided an opportunity to look at autism from a number of developmental and multidisciplinary health perspectives. It was great to share and hear the reality of clinical practice in the area, buoyed by the drive and acumen of those who work in the field, in addition to the hope that ongoing multi-centre research offers in the area.

By Cathy Franklin Consultant Psychiatrist



Left: Dr Jacki Small

Right: Charmaine Driver





Left & Right: Hypothetical with Dr Cathy Franklin, Dr Michelle Garnett, Dr Michael Keates, and Dr Aline Smith

Below: Sister Angela Mary Doyle







Left: Dr Torbjorn Falkmer

Right: Dr Kate Sofronoff







Far Left: Prof Nick Lennox

Middle Left: Dr James Morton



Middle Right: Dr Mike Gattas



Far Right: Tania Malouf

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https://www.edx.org EDx is an international collaboration of universities to provide free tertiary courses to anyone who wants to take them.

We are working hard to develop the first international course about the lives of people with intellectual and developmental disability and their families around the world, and how they look after their health.

This course is about hearing the voices of people with IDD around the world, their families, their disability and health supporters. The course is called *AbleMe101 - Through My Eyes - Intellectual and Developmental Disability around the world*. It will help students to see people with IDD as people first, see their lives, their truth, beauty and their contribution to society. The course will help students to think about how positive attitudes can keep people healthy, be better informed and how to be a better advocate or disability or health professional.

The course will be free, can be taken by anyone around the world, and will be online permanently.

Keep an eye on UQx site for news of our course - http://uqx.uq.edu.au/

QCIDD is working hard to get their project for the Autism CRC up and running. Prof Nick Lennox is the project leader, Dr Kate van Dooren is the project manager, and Ms Cindy Nicollet is a PhD candidate.

QCIDD sits within Program 3 of the Autism CRC aims to improve opportunities for people with autism spectrum disorders (ASD) to successfully transition to post school life, participate in higher education and employment, and identify best practice in physical and mental health management.

Our project aims to enhance health and wellbeing among adults with autism spectrum disorder (ASD) and their families. It focuses on the identification and management by general practitioners, psychiatrists and other mental and allied health professionals, of the physical and mental health issues frequently associated with ASD.

The interventions developed and the outcomes of this project will be informed by the longitudinal study of adults with ASD (being conducted out of NSW), which will track over three to four years the physical and mental health, wellbeing, life roles, time use, satisfaction, employment, community access and participation of adults.

We are kicking off with qualitative interviews of adults with ASD and health professionals – keep an eye out for our recruitment information if you or someone you know might be interested in participating!



On September 4th, Professor Nick Lennox launched the information sheets developed by Epilepsy Queensland and QCIDD for people with epilepsy and intellectual disability, their families and health practitioners.

These are available on our website – <u>www.qcidd.com.au</u> free of charge and easily downloadable.

Thursday 4th September 2014 2:00pm - 6:00pm

Russell Strong Auditorium Princess Alexandra Hospital Ipswich Road Woolloongabba



Director of the Centre to Advanced Imaging(CAI) at the University of Queensland



rector University of ueensland's Centre r Intellectual & evelopmental Disability (CIDD)

Epilepsy and intellectual/ developmental disability: the keys to successful management

- Managing complex epilepsy in people living with intellectual disability
- Sudden Unexpected Death in Epilepsy
- Practical care of people with epilepsy including administration of Midazolam
- How to prepare for the NDIS





www.epilepsyqueensland.com.au

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The Walk and Talk Program has officially been launched!



EXERCISE: Mark Henderson and Troy Singleton enjoying a jaunt along the Esplanade with the Endeavour Foundation's Chelsea Saldumbide and Thomas Orr. Picture: STEWART MCLEAN

Buddies wanted for walks

MICHAEL SERENC

PEOPLE with a disability are being urged to discover the great outdoors as part of the Endeavour Foundation's "Walk and Talk" program.

The not-for-profit disability support organisation is calling for more volunteers, or "walking buddies", to take those with a disability out for half-an-hour of walking and conversation each week. Cairns occupational therapist and program volunteer Thomas Orr said the initiative gave the disabled a way to be socially included.

"People with an intellectual and development disability find it very difficult to interact with the community and mainstream aspects of life," he said. "So giving them this opportunity, even though it's only once a week, is such a big thing for them to have bit more of a sense of normality about themselves."

Mr Orr said people with disabilities were motivated to exercise, but needed the encouragement of volunteer support workers and family.

"It's just being able to give them the chance to do it in a safe environment, which is why they need someone with them," he said.

The Walk and Talk program was developed in conjunction with the Queensland Centre for Intellectual and Developmental Disability. To help, call 1800 63 40 40 or email volunteering@endeavour.com.au.

Congratulations Peter!

Peter McMeekin has been one of QCIDD's tutors for 10 years. QCIDD nominated Peter for an award at the recent Disability Awareness and Opportunity Expo by Special Care Central Inc, and he won an Achievement Award!!

Peter proudly accepting his trophy and certificate from Yvonne Campbell from Special Care Central www.specialcarecentral.com.au



Brisbane Fringe Festival - Art of Science

Cindy Nicollet & Miriam Taylor presented at the **Brisbane Fringe Festival** Art of Science night on 19th August 2014 at Avid Reader in West End. It was a full house. Their presentation focusse on their work with QUT Urban Designers on "Sensing the city: Examining Urban Jungles – cities, people and neurodiversity". It was covered in the Weekend Edition -<u>http://m.theweekendedition.com.au/captured/art-of-science/</u>









Some links of interest

- World Report on Disability and Intellectual Disability <u>https://www.youtube.com/watch?</u>
 <u>v=RWA2QeDo76Q</u>
- SPRUNG!!! Integrated Dance Theatre Inc <u>http://sprung.me/_& https://www.facebook.com/</u> <u>sprungdance</u>
- * Have you seen our person-centred website? <u>www.qcidd.com.au</u>
- * Immunization not just for kids!! <u>http://blog.thearc.org/2014/08/29/immunization-month-just-kids/?utm_source=rss&utm_medium=rss&utm_campaign=immunization-month-just-kids</u>
- Improving Outcomes for People with Intellectual Disabilities <u>https://www.youtube.com/watch?v=_s2PSTlfoTQ</u>
- * A Health and Intellectual Disability Study on Obesity and Health Risk Behaviours https://www.youtube.com/watch?v=hHuJA3kKhlM
- Lifestyle In Supported Accommodation (LISA) <u>http://www.lisainc.com.au/media_release_by_jacksonryan</u>
- * Information Booklets for Families of Young Children with Disability. All in PDF downloads <u>https://publications.qld.gov.au/dataset/my-child-has-information-for-queensland-families-of-young-children</u>
- * Labradoodles have oodles of benefits for children in the classroom <u>http://www.abc.net.au/news/2014-08-03/labradoodles-have-oodles-of-benefits-for-children/5644614</u>
- * Mental Health and Intellectual Disability <u>https://www.youtube.com/watch?v=otpxh1Ghy8I</u>
- * What about our YouTube channel? <u>https://www.youtube.com/</u> <u>channelUChCUpCHdvnHqAf8SBOuV_tA</u>
- * Dive into our free online course for support workers about being a great health advocate for people with disability <u>http://ndshealthandwellbeing.avana.com/</u>
- * Intellectual Disability training videos <u>http://www.aci.health.nsw.gov.au/networks/intellectual-disability/id-training-videos</u>
- * Are you interested in receiving information about Sexual health and Disability? QCIDD's Education Coordinator Miriam Taylor, is currently setting up a new email contact list and would like you to be apart of it! <u>m.taylor@uq.edu.au</u>
- * Buy, Swap, Sell Hospital and Caring equipment <u>https://www.facebook.com/groups/1556444567916943/# = </u>