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THE UNIVERSITY
OF QUEENSLAND

Apr-Jun 2013

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



QCIDD CLINIC UPDATE

Dear QCIDD Supporters,

Winter is well and truly upon us, and apologies about the late publication of this issue of our quarterly Newsletter.

Our waiting list for the clinic continues to grow, and is now into **2014**.

Prof Lennox is booked until the end of January, 2014, Dr Lane until the end of July, Dr Eastgate until the end of September 2013, and, Dr Franklin until December, 2013.

However, don't let this stop you from sending in a referral or requesting appointments, our clinic is still experiencing a high demand for service.

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



Students Coming to QCIDD: Introducing *Meghan!*

Hello! I am Meghan from New Hampshire, in the United States. I am a Biology student at the University of New Hampshire working towards becoming a dentist. I am here in Australia working with **QCIDD** on an oral health research project gaining the perspectives of adults with intellectual disabilities about oral hygiene.



Across the general public and disadvantaged groups it is an overlooked part of overall health. Many adults with intellectual disability have little access to dental care and may need more support to understand the importance of brushing their teeth every day. I want to one day contribute as much as I can to being able to support these individuals in my dental practice and understanding their view is the first step.

PHAA Social Inclusion

On April 15th and 16th, QCIDD presented our research at the **PHAA National Social Inclusion and Complex Needs Conference** in Canberra. We delivered oral presentations on prisoners with intellectual disability, the Walk and Talk Program, The Ask Project and our follow-up study on Challinor residents. Two posters were on display, one on our **eHealth project** and another on **Sexuality Issues in People with Intellectual Disability**.

The opening speakers, **John Falzon** from the Social Inclusion Board, **Robert Tickner** from Red Cross and the Hon Member **Mark Butler** MP, provided an insight into the complexity of challenges that face the most vulnerable in our community. On Day 2 we had excellent keynote presentations from **Tom Calma**, whose most recent previous position was that of Aboriginal and Torres Strait Islander Social Justice Commissioner at the Australian Human Rights Commission; **Robyn Kruk**, Chief Executive and Commissioner of the National Mental Health Commission; and Christine Boyce who in 2008 was awarded the RACGP “GP of the Year” in recognition of her work with refugees. While represented in all of these three groups, there was no invited speaker who spoke about the specific needs of people with intellectual disability who make up approximately 3% of the Australian population. Our presentations were all well accepted and we felt that by being there we had in a small way raised the profile of intellectual disability on the Australian public health agenda.

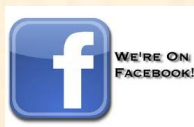


Impact of Sensory Processing on Behaviours

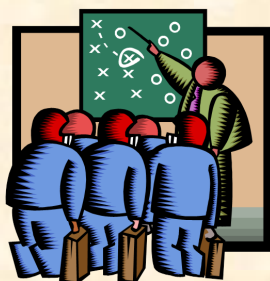
Vivienne Williams (Kids Matters)
and Cindy Nicollet (QCIDD)



On the 18th June, **Cindy Nicollet** (Behaviour Support Consultant/Associate Lecturer, QCIDD) and **Vivienne Williams** (Principal Occupational Therapist, Kids Matters), presented a four hour workshop on Sensory Processing and its Impact on Behaviour. The workshop provided understandings of behaviour from an OT and Psychologist perspective as well detailed information in relation to sensory processing and the way individual processes information from their world can impact how they interact and engage with their world. The workshop was also interactive, allowing participants to engage in discussions around case examples and other activities. Feedback from participants, which included parents as well as staff working in the disability sector, was positive and since the workshop there have been requests from other service providers to conduct the workshop later in the year. If you would be interested in finding out more information about the workshop, please contact Miriam Taylor (Education Coordinator, QCIDD) – m.taylor3@uq.edu.au.



Why not find us to receive up to date information as it arrives, also see the new ideas, research and interesting facts about our work!



Health and Intellectual Disability Symposium

and Seminar Series 5-9 August 2013

Proudly presented by the

School of Occupational Therapy and Social Work Curtin University

in partnership with the Disability Services Commission

and the Mental Health Commission.

<http://healthsciences.curtin.edu.au/health-and-intellectual-disability-symposium.cfm>





THIS RIDICULOUS JOURNEY WITH WADE



On July 5th at 2.15 we were ever so pleased to be holding this baby boy in our arms breathing, crying and attaching to my breast. This was such a relief for both of us as Wade's older sister was stillborn 18 months prior.

During my pregnancy with Wade, it was detected I had gestational diabetes and at 20 weeks a scan picked up that he had an enlarged right kidney, so after this it was decided I would have a scan every 2 weeks just to keep an eye on things. Other than that I breezed through the nine months knitting, sewing and learning to ride a motor bike and drive a car as it was thought I may need my driver's license with this bub.

So now I looked forward to spending the next 7 days in hospital learning to feed and care for my new baby boy, I very quickly learnt he liked to lie on my chest with his dummy if he wasn't feeding. He seemed contented enough when he was with me during the day. But at night when he was taken back to the nursery the midwives were forever coming to get me saying "Mrs Mahon your baby has wind, you need to burp him properly. You haven't fed him properly."

So by day four, I was yearning to get home, surely it couldn't be this hard and once we are in our own environment it can only get better, right! The next couple of nights, I spent pretty much most of the night in the nursery feeding burping my baby, midwives said he was lazy and I needed to stimulate him more to keep him awake. I never really felt this was a problem just thought with practice all would get easier. I was really just so excited to finally be a mum and hold him.

That I dare not complain!

So at last we get to go home four and a half west of Rockhampton to Springsure, knowing we had to take weekly wee samples to the local hospital and daily doses of antibiotics to prevent infection. And a monthly nine-hour round trip to the Paediatrician in Rockhampton, piece of cake, right!

My mum stayed a day or two then home she went. Finally our baby to ourselves. Wade continued to feed and sleep half hourly on good days. He was always hungry! It was worst at night and the dummy; I lost my cool with it one night and threw it away. Week-ends we took turns at catching up on sleep. I also learnt not to complain to mum. She said I needed to be more patient; babies do cry and they do spend a lot of time feeding. At three months, I finally gave in and fed him some Farex, even though the book and nursing mothers said no, this did help a little. Finally at 9 months I stopped feeding him myself I was so exhausted, bottle it was. He seemed much more satisfied. Looking back, it was much easier for him to feed from the bottle.

So the monthly four and a half hour trips to Rockhampton were very long but Wade was a good sleeper in the car, thank God, as these trips were just the two of us as my husband Laurie was working.

He was a very beautiful smiley happy baby generally. And one thing he loved from a very early age was books I would read to him all the time. Wade may not have reached his milestones like my friends babies but he did reach them. Shortly after Wade's second birthday it was decided they would send us to the Mater Children's Hospital in Brisbane to have his right kidney removed and to have urinal reflux fixed at the same time. He was such amazing patient. Laurie and I were obviously anxious as he underwent the surgery and time seemed to drag. He spent a good while in recovery and was finally let back to the ward. Two hours after surgery and listening to the Wiggles on TV, Wade started to dance while lying in his bed. Twenty four hours later, he was up and mobile with his tubes and bags and playing in the ward.

Shortly after returning home from Brisbane Wade got to meet his little sister Jacinta. This is when I really realized just how different things were between babies. And I was beginning to notice Wade's speech, his gross and fine motor skills to be somewhat delayed.

As Jacinta approached her second birthday, she was really starting to overtake him and he was now learning from her. Wade talked heaps, most of it we could not understand, I always tried never to discourage him with his speech, even though it was very hard to communicate at times. I had talked to Wade's paediatrician on numerous occasions in regard to the delay in some areas of Wade's development but he did not seem concerned at all and I was impatient.



When Wade turned four, we enrolled him at the local community kindergarten, where he attended three morning sessions a week. This is when it was brought to my attention by the kindergarten teacher he had behavioural problems (pinching, biting and pushing). She questioned whether he was getting too many preservatives in his diet and recommended we go to a naturopath which we did and came home with a lactose wheat free diet which we trialled for one month. We stopped as Wade became very lethargic and irritable so it was obvious this was not the problem. Finally our family doctor picked up he had an ear problem and thought he should be referred to ENT. On a waiting list we were put down for grommets. Finally he has them in! Wow what a difference this makes as he had never heard the toilet flush, the little boy next door cry and the list of things went on. So he was missing so much in picking up basic sounds whilst learning to speak. On the journey home from Rockhampton he sat in his car seat talking, never shut up, he would say the same word over and over till it sounded clear. The word was far from the word any mother wanted to hear coming out of their child's mouth F***!! OMG. His speech came along leaps and bounds with some speech therapy and more 140km round trips.

So now we are off to pre-school, glad to be leaving the turbulent kindergarten year behind us. The first day was terrible - he threw a tantrum I couldn't get him across the road to the pre-school (I can honestly say this was his first tantrum ever). The teacher-aide kindly came to my rescue and so nicely informed me they had been forewarned of Wade and his bad behavioural issues. Oh great! Finally we coaxed him over to the pre-school, lucky that teacher aides coaxing skills impressed me! The year was a relatively stress-free year; the issues of the past year didn't seem to be a problem this year. He was assessed and appointed some hours for extra teacher-aide help for which an angel was appointed, Mrs. Kavanagh.

Finally, we are at big school starting year one. His teacher-aide worked tirelessly with him trying to teach him his letters, words and numbers. The learning support material given to help Wade read was not working and when in Grade 2 he still couldn't read! Finally also frustrated about this Mrs. Kavanagh said to me "Don't say anything but I have dug through a box of old books I had at school and I am going to give this a go." Bingo! She had that little boy recognising sight words spelling and reading and within about six months he could read an article in the newspaper! Prior to this if someone asked if he could read something, he would say yes and read what he thought it was very confidently regardless. So this was a massive milestone reached and one he did with so much pride, he had so many books at home he could now read! By now it was becoming more and more evident that Wade did really have learning development issues. I once again brought this to the paediatricians attention taking a long his assessment from school. I was told to have patience, everything was ok. Wade could not ride a bike and I would sit him on an exercise bike with the seat right down bandage his feet to the pedals and sit on the floor and help him learn to pedal the bike. When finally he had enough strength and learnt the peddling action, we put him on his bike with trainers he was so excited.

Already a long the journey family and friends are saying to us he is spoilt he needs more discipline, it is us with the problem not the child. Laurie and I know there is a problem we have no idea what. Our goal for Wade was by the time he leaves school that he is a respectful, independent person with a job even if it is only mowing lawns. So from about seven years of age this was our goal. And sadly at school as his peers matured he was becoming socially unaccepted, so he was spending more and more time on his own in the library (THIS BECAME HIS SAFE PLACE). He was bullied severely in the playground.

At the end of year four, Laurie started a new career with the Queensland Ambulance Service. So we moved to Bundaberg, where we enrolled both Wade and Jacinta into Norville State School (this school was highly recommended to us for children with learning difficulties). The first 12 months was really full on with his teachers trying to teach him how to play and communicate with others. The most frequent question asked was "What has he been diagnosed with?" (He is just slow at learning, you need to be patient). A great bunch of teachers worked tirelessly over the next three years to ready Wade for the next big step in life high school. In year seven he was diagnosed with scoliosis and had surgery to fix rods and hooks to his spine to straighten him up. A move 50km west of Bundaberg to Gin Gin with Laurie's work was a positive in Wade's schooling as the high school special education unit was very highly regarded in the region.



Wade became very confident in himself and made some beautiful friendships in his time at high school. It was noticed in early high school he developed an eye blinking habit and it became progressively worse. Our local GP referred us to the local Paediatrician. He was diagnosed with anxiety so with the help of a psychologist, things were put in place to help alleviate this. Along the way I plucked up enough courage tell the doctor about our journey so far and if he could be tested to see if anything showed up genetically. She never hesitated, it was done and finally the diagnosis. We knew nothing about Fragile X and no one could really answer my questions at the time. I was left to Google on the net and found American based literature; this was enough to start my learning and helping to understand Wade. I guess it confirmed we were doing ok to a degree and also helped us in areas we struggled badly in with Wade. The biggest struggle is he looks so normal, so people expect normal.

Because of this people don't show understanding and he is so capable compared to so many other young people.

Senior high school approached very fast, and with this we realized how much work still needed to be done to help Wade be able to be as independent as possible in his next phase of life. Now this is where my education really starts! Through a work program with the help of the school he started work experience at the local BP. THIS WAS A DISASTER and did very little for his confidence, it was said he was extremely lazy and would not stay focussed and on task. But the agency that was given the funding to help him stay in this job was not seen to be supporting him as they should have been. So we signed up with a different job agency with much better outcomes. He was finally placed in an Italian restaurant as a kitchen hand. He would work one afternoon during the week and Saturday lunch period so all up about 10hrs a week which he enjoyed and he always looked forward to going to work. He stayed in this position for about twelve months. The other big obstacle was Wade always wanted to be just like his peers, so to him the next big to do on his list was obtaining his learners! And yes true to Wade's grit and determination he obtained his learners'. I think he was about 21 when he finally got his P's . Wade finally graduated from year 12 very proud of himself and with every right. He had worked so hard at everything he tried. By the end of January he was lucky enough to have scored a job with a friend cleaning shift workers rooms in a camp setup this was a great opportunity he worked well in a team. Unfortunately this situation changed when our friend moved away and of course others were not interested in taking him under their wing so to speak. Finally he was asked to leave so it was back to job searching through organisations that were only meeting just what they needed to, so it enabled them to get their funding. It doesn't matter that he was capable of 20-30 hrs work he would get 12hrs a week spread over 3 days which you need to make 104km round trip to get him there and back.

Trying to keep him busy learning new tasks so he was employable has been so hard; honestly there is very little genuine support for these kids/ young adults. He did a living skills course with a government funded organisation. At this stage in his life he also wanted to live outside the family home independently. We finally had him placed in a living situation with other young adults like himself, probably not as independent or as capable as Wade. This proved to be stressful for all involved and after about 12 months he moved back home again. He did a TAFE course at one stage in construction so he may get a job as a labourer maybe. He is always so eager to make friends and be accepted by people. It was found he was lending his car out during the day to some not so nice students and on his prac days in the work place he was being egged onto unsafe practises with a staple gun etc. It was decided this was not working so he was placed in a different work place for the remainder of his course. Over a couple years he had talked off and on about doing a traffic control course but at no stage did any organisation he was enrolled in help him get into a course. He was finally working cutting rags for Lifeline when he sourced a course himself and enrolled into it paying the \$380.00 he saved to do it. The job search organisation he was enrolled with at the time really didn't show him the support. So he did the course and passed, obtaining the certificate to be able to perform this task. He also at the end of this course filled out a job application form for a local Bundaberg business called FNQ Security.



A phone call came one morning from Moe, an employee of this business, asking if Wade could come into Bundaberg for an interview and if I would also come along to help with filling out forms. (Obviously someone understands Wade needs some support was my instant thought). That day we went into Bundaberg to FNQ met Moe and filled in all the appropriate forms for Wade to start employment with them as soon as there was work available and suitable for Wade. Moe had worked with a life styles group engaging young people with disabilities into a variety of activities, hence the understanding he showed regarding Wade. He was very quick to point out his strengths and that he should always ask questions if he was ever unsure of a situation. So within a couple weeks Wade was given some trial days by the owners Lloyd and Marrian Finnis, he has now been working with FNQ for nearly 12mths. During this period FNQ'S office door has been opened to us with any concerns we may have and likewise they have been open with us with any concerns they have regarding Wade. Wade has worked with several different employees within FNQ and they are all very accepting of him. He loves going to work every day and if he has not been called into work he is calling them asking for work. Wade has exceeded our expectations with work at times working 7 days straight and is up at 4.30-5.00 each morning and can finish as late as 6.00 pm. This group of people have made a big difference in Wade's life.

In trying to help Wade in the last couple years to find a way to help with his concentration this has led me to find Dr Nick Lennox at his clinic at the Mater Hospital. Wow! Yes, the road has been a little bumpy along the way but with Dr Lennox help we are finding the causes of Wade's lack concentration and wandering off task a lot.

During the past 6 months Wade has been diagnosed with epilepsy, and is under investigation for sleep apnoea, neither complimenting the other. Firstly, he has never displayed anything remotely like a Gran Mal seizure. Past events like riding his bike into a girl in plain view on the bike track, driving his car into a fuel pump and stopping in the middle of mowing the lawn numerous times with no explanation of why things like this could happen suddenly appear to be petit mal or absence seizures.

The impact on Wade has been huge. He has had to stop driving, a major part of his independence and social life and something that naturally, he was very reluctant to relinquish. This adds extra hours to my day as I now have to drive him to and pick him up from work. More long round trips (sigh). His work has been very supportive and the patience of these guys is greatly appreciated. He also has the challenge of losing about 10 kg in the next couple of months to hopefully avoid the need for a CPAP machine.

The journey so far has been a battle at times and somewhat ridiculous, but we have only been driven to help Wade achieve his dreams, the best quality of life he can possibly achieve whilst being accepted socially by others in the wider community. One thing Dr Nick Lennox has reinforced - it is up to us as a family to put the safety net together, as no one is as driven as the loved ones. I know we tend to overprotect him but at the end of the day we are trying to keep him safe.

There is still a lot to be done as Wade would love to have his own place to live. The one thing I am totally sure about Wade is, Laurie and myself have been bloody minded and determined to succeed as parents, HE IS EVEN MORE DETERMINED THEN THE PAIR OF US TO SUCCEED!

Many thanks to Anne-Maree for sharing her story about Wade.



UQ Researcher Presenting at an Advisory Ethical Meeting for the Pope



Published: Friday, 7 June 2013

A researcher from The University of Queensland will present at an ethical meeting for the Pope to persuade governments to provide substantial resources to improve the health and wellbeing of people with an intellectual disability.

Professor Nicholas Lennox, Director of UQ's [Centre for Intellectual & Developmental Disability](#) has been invited to present his paper 'Promoting Well-Being in Persons with Intellectual and Development Disabilities' at the 6th International Colloquium of the [International Association of Catholic Bioethicists](#) (IACB) in Italy from 9-14 June.

Professor Lennox said access to high quality healthcare remains a significant challenge for people with an intellectual and development disability (IDD) and their families.

"Beyond attitudinal and access barriers to healthcare, are the challenges around clinicians gathering clear and accurate health information from the individual," Professor Lennox said.

"For many people with IDD: recall, communication and speaking up for themselves about their mental or physical sensations or feelings is difficult and for some it is impossible."

When writing his paper, parents and medical clinicians of people with IDD across Australia were asked for their view on whether people with IDD experience the right to be valued, the right to health, the right to high quality healthcare and the right to self-determination and inclusive decision making.

"They pointed to deficits in our current ways of addressing the health and health care needs of this group and perhaps unsurprisingly respondents agreed on most salient points," he said.

"The current physical and mental wellbeing of people with IDD falls well short of the standard experienced by other members of the population, such that in truth none of these questions can be answered in the affirmative.

"People with intellectual disability confront profound devaluing from pre-conception to death.

"This is reflected in their health, healthcare and their ability to powerfully participate in actions to gain and maintain their wellbeing throughout life."

Professor Lennox hopes that the Colloquium will use whatever mechanisms that are available to insist governments direct substantial resources to improve the physical and mental health and wellbeing of children, adolescence and adults with intellectual disability.

Professor Lennox has also been instrumental in development of the Developmental Disability Therapeutic Guidelines Book, performed the world's three largest randomised controlled trial in people with intellectual disability for the Comprehensive Health Assessment Program (CHAP) and Ask health diary, and lead the writing of the health intervention segment of the recently released WHO World Report on Disability. In 2012 the Australasian Society for Intellectual Disability (ASID) recognised his work and he was awarded the honorary title of ASID Fellow.



*Professor Nicholas Lennox
Director of UQ's Centre for
Intellectual & Developmental
Disability*

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Of Interest:



- ∞ <http://www.bbc.co.uk/blogs/ouch/>
- ∞ http://www.health.nsw.gov.au/pubs/2012/service_framework_2012.html
- ∞ http://info4carers.com/images/docs/2011%20You%20Are%20Not%20Alone_eBook.pdf
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- ∞ http://www.betterhealth.vic.gov.au/bhcv2/bhcarticles.nsf/pages/ten_tips_to_cut_down_on_salt?open&utm_source=homepage&utm_medium=site&utm_term=ten_tips_to_cut_down_on_salt&utm_content=panels&utm_campaign=rotations
- ∞ http://www.wwda.org.au/marieclaire_article_june2012.doc
- ∞ www.call4cutz.com
- ∞ <http://www.streetsmartaustralia.org/findrestaurant>
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- ∞ http://www.betterhealth.vic.gov.au/bhcv2/bhcarticles.nsf/pages/Body_image_and_diets?open
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- ∞ <http://www.disabilityonline.org.au/homepage>
- ∞ http://www.nps.org.au/bemedicinewise/antibiotic_resistance/antibiotic_awareness_week
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- ∞ www.bookpal.com.au/
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- ∞ www.pathwaystoresilience.org
- ∞ <http://www.fragilex.com.au/>
- ∞ <http://www.pwc.com.au/industry/government/assets/disability-in-australia.pdf>
- ∞ <http://www.ntw.nhs.uk/pic.selfhelp>

Quote

" FRAGILE X SYNDROME DOES NOT DEFINE YOU,
IT IS A VERY SMALL PART OF WHAT MAKES YOU WHO YOU ARE.

MANY MORE ASPECTS COME BEFORE THIS DISORDER, SUCH AS A SENSE OF HUMOUR, KINDNESS, EMPATHY,
COMPASSION, GENEROSITY, INTELLIGENCE TO NAME A FEW.

ALSO YOU ARE WORTH KNOWING AND BEING A PROUD OF THE PERSON YOU ARE."

Megan Levy, 2012