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THE UNIVERSITY
OF QUEENSLAND

Sept —Dec 2012

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.



QCIDD CLINIC UPDATE

Dear QCIDD Supporters,

Hello and welcome to the last issue of QCIDD's newsletter for 2012!

Hasn't this year travelled fast?

Our waiting list for the clinic is well into 2013, Prof Lennox is booked until December 2012, Dr Lane until mid December 2012, Dr Eastgate until late February 2013, and Dr Franklin until late April 2013. 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

The staff of QCIDD wishes all of our colleagues, friends and supporters the very best of the Festive Season and looks forward to working with you in 2013.



Students Coming to QCIDD



This month six students will come to QCIDD under the UQ Summer Research Program which provides an opportunity to gain research experience working alongside academics and researchers. By participating, it is hoped that students will extend their knowledge of the field of intellectual disability and develop their analytical, critical thinking, and communication skills. We have four students from The University of Queensland as well as two students from other Australian universities coming for up to 10 weeks over the summer vacation period. They will be working on different topics involving people with intellectual disability including a review of the literature on hand-held health records; the implementation of a student-run workplace health clinic; the transition of adolescents from secondary school to adulthood; life quality and behaviour post-institutionalization; alcohol and drug taking in prisoners and social-isolation in families.



If you are also on Facebook <http://www.facebook.com/QCIDD>, and Twitter @QCIDD, 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!



Walk & Talk

Improving the physical activity and social engagement of people with a disability

A step in the right direction

The Walk & Talk program is a 12wk fitness interactive university research project aimed at improving physical activity & social engagement of people with a disability.

The program pairs community volunteers known as Walking Buddies with people with a disability (participants) across South East Queensland and Sunshine Coast areas.

Walking Buddies will be required to commit to walking with a Participant, once a week for up to half an hour around the participants local neighbourhood during the 12wk program.

It is anticipated that the outcomes of the program will;

- Enhance the health and wellbeing outcomes for all.
- Develop a stronger community relationships.
- Increase the community's understanding and knowledge of people with a disability.
- Provide useful research leading to great in-depth knowledge about the benefits of physical activity.

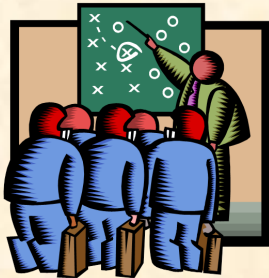


Health & Wellbeing

PROGRAM Live · Work · Play

For more information & community members wishing to volunteer to be a Walking Buddy may register their interest by contacting Endeavour Foundation's Volunteering Department on;

07 3908 7253 or
volunteering@endeavour.com.au



September to December Presentations

Prof Nick Lennox

Love in the time of Randomised Controlled Trials, 2012 Health for Living ASID, Perth West Australia

CHAP Workshop, Perth Western Australia

Chronic Disease Panel Discussion, People with Intellectual Disability, Mater Hospital

Love in the time of Randomised Controlled Trials & beyond, Endeavour Foundation's Speakers Series 2012, Sydney

Hidden medical pathology in people with intellectual disability: Things you don't want to miss, Special Interest Group in

Intellectual and Developmental Disability Psychiatry, QLD with Disability Network

GP Registrar training on intellectual disability, CSQTC, Toowoomba

Prof Nick Lennox & Julie Gibson

Impact of Developmental Disability across Life Cycle, Child and Adolescent Psychiatry Registrars, RCH - Children's health service - Child and Adolescent Psychiatry

Prof Nick Lennox & Miriam Taylor

QCIDD clinic, research, education, advocacy, CHAP, How to promote health to support workers for the people they assist, Training Centacare Management, Lavalla Centre

Miriam Taylor

Human Movements, Friendship and intellectual disability, St. Lucia

QCIDD Family Day, Transitions from Adolescent to Adulthood, Mater Hospital

Disability Week Display, Mt Gravatt

Friendships and Relationships Group, MICAHA at Trinity Place

Sexuality & Health, MBBS, St Lucia

Disadvantaged Patients, MBBS Gp rotation, UQCCR Herston

How people with disabilities are treated in hospital and health services, Hot Topics, QDN

Lighten Up to a Healthier Lifestyle, Healthy Living Workshop, Common Ground

Miriam Taylor & Dr Cathy Franklin

Chronic Disease Panel Discussion, People with Intellectual Disability & Chronic Disease, Mater Hospital

Dr Gillian Eastgate

Bodies and private body parts; All the names for sex and body parts, Trinity Place

Cindy Nicollet & Claire Mitchell

Introduction to Intellectual Disability, Psychology year 2 Students, St. Lucia

Cindy Nicollet

Urban Jungles: Are our Urban Environments Excluding People with Neurodiversity, 5th Alliance for Healthy Cities Global Conference 2012, WHO Western Pacific Region, Brisbane Convention Centre



Russell Booyesen

Russel started swimming at the age of 10 years old competitively with SPECIAL OLYMPICS, He trained once / twice a week.

At the age of 12 he was selected to represent QLD and he competed at the SPECIAL OLYMPICS JUNIOR NATIONALS in the ACT where he won GOLD SILVER AND BRONZE MEDALS and set new Personal Bests for himself.

At fifteen years old he was selected to represent QLD and he went to the SPECIAL OLYMPIC SENIOR NATIONALS in Adelaide where he won GOLD SILVER AND BRONZE medal and set new Personal Bests for himself.

Russell has represented QLD SCHOOL BOYS for swimming and competed very well.

At sixteen years old he competed at the INAUGURAL DOWN SYNDROME NATIONAL GAMES at NOOSA AND WON AGAIN ALL THREE MEDALS and set new Personal Bests again for himself.

From competing at NOOSA he has been selected to Represent Australia at the DOWN SYNDROME WORLD CHAMPIONSHIPS in ITALY 2012 NOVEMBER 15TH. He will be competing against the WORLDS best in seven events.



All of this swimming and competing has given Russell very strong self pride on what he has achieved, it allows him to have faith in himself that if he trains hard , works hard and he will succeed in anything he puts his mind too. Russell enjoys the routine of going to training and he tells his parents it enables him to relax and have fun.

Russell currently completes 4 x 2 hours sessions in the pool a week and

2 x gym session a week to get him ready for Italy.

Congratulations Russell from the QCIDD Team!



Sensory Room For Hire



The individual accessing the room must have a staff member/support person with them at all times. The person assisting the individual will need to attend a training session at Multicap about using the equipment prior to hire. The cost of the training session is charged at an hourly rate of approx. \$27.00.

The cost to hire the room is charged at an hourly rate of \$15.00

The organization supporting the individual will be the 'hirer'. They need to have up-to-date public liability insurance and a copy of an up-to-date insurance certificate needs to be made available to Multicap before use of the room.

Multicap also has a Sensory Room Hire Agreement that needs to be signed by the hirer prior to use. The party with the public liability insurance is the name that should be placed on the hire agreement.

In terms of room bookings, you can make these on a weekly, fortnightly, monthly basis or just as a one-off.

www.multipap.org.au



QCIDD's Miriam Taylor is receiving an award!

As part of Family Planning Queensland's 40th birthday, they have established the **Ruby Roll of Honour** to celebrate innovators, trailblazers and practitioners who have made a difference in sexual and reproductive health, women's health, healthy relationships and child protection in Queensland over the last four decades.

Miriam has been selected as an inductee to the **Ruby Roll of Honour** as a result of her significant contribution in the areas of access to sexual health awareness and education for people with a disability.

All inductees to the **Ruby Roll of Honour** will be announced and recognised on Tuesday 27 November, at 6.30pm at a celebration following FPQ's AGM.

This special event will be held at the University of Queensland School of Pharmacy, Pharmacy Australia Centre of Excellence, 20 Cornwall Street, Woolloongabba. So come along and congratulate Miriam in her excellent work!



Miriam's Thankyou Speech

"This is a great personal honour. I thank the team at Family Planning Queensland for this accolade and congratulate them on their 40 years of dedication to educating us all about sexuality and sexual health. The work of promoting the rights of people with disabilities to sex education and reproductive health checks has been and is being done by many, not least my colleagues past and present at FPQ, QCIDD, NDS, and QND.

The beauty of growing older is that we can look back and see progression and regression. Our children without disability now learn more about their bodies and their rights. Yet, freedom of sexual expression for people with intellectual disability remains a distant hope. Our primal fear of difference creates a society which disallows their having healthy relationships, it denies them education about their bodies, and our society still sterilises young men and women with intellectual disability, all because we fear difference.

It is my strong belief that people with disability are us and we are them, and as such, you and I should have no less expectations of their living exciting and meaningful lives filled with friendship, love, and companionship.

Thankyou once again for this honour. I offer my thanks to the many out there who continue to challenge the status quo and to those who dream that one day the differences between us will be invisible."

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
- ∞ <http://www.communitydoor.org.au/how-to-hear-me>
- ∞ 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>
- ∞ http://www.betterhealth.vic.gov.au/bhcv2/bhcarticles.nsf/pagesPhysical_activity_tips_to_overcome_the_barriers?open
- ∞ http://www.betterhealth.vic.gov.au/bhcv2/bhcarticles.nsf/pages/ten_tips_to_cut_down_on_alcohol?open&utm_source=healthyliving&utm_medium=site&utm_term=ten_tips_to_cut_down_on_alcohol&utm_content=link&utm_campaign=rotations
- ∞ http://www.betterhealth.vic.gov.au/bhcv2/bhcarticles.nsf/pages/Body_image_and_diets?open
- ∞ <http://www.abc.net.au/rampup/articles/2012/10/15/3610533.htm>
- ∞ <http://www.disabilityonline.org.au/homepage>
- ∞ http://www.nps.org.au/bemedicinewise/antibiotic_resistance/antibiotic_awareness_week
- ∞ <http://www.givenow.com.au/>
- ∞ <http://www.fpq.com.au/pdf/EV-FPQMasterClassTrafficLights2012-13.pdf>
- ∞ www.bookpal.com.au/
- ∞ <http://www.bowelcanceruk.org.uk/resources/bowel-health-and-screening/>
- ∞ www.pathwaystoresilience.org
- ∞ <http://www.fragilex.com.au/>
- ∞ <http://www.pwc.com.au/industry/government/assets/disability-in-australia.pdf>

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

Disability Online

AUSTRALIA'S DISABILITY HUB



Disabilityonline.org.au

Service Providers

Carers Help

Advocacy

Funding

Aids & Equipment

Holidays

Recreation

Service Standards

Active Support

About Disabilities

Communication

Behaviour

Accommodation

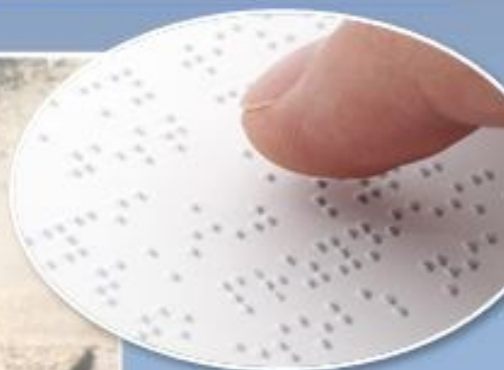
Respite

Diets

Restrictive Practice

News

Transport



WHAT'S ON

SPORTS

SOCIAL GROUPS

THE ARTS

SUPPORT GROUPS



Twitter – [DisabilityO](#)
Facebook-[DisabilityOnline](#)
Disability.Online@gmail.com

Transition from adolescence to Adulthood, QCIDD Family Day 9th August 2012, This is a paper presented by one of our parents at the recent QCIDD Family Day.

As part of her presentation, Pat read some excerpts from her book 'Dear Dr Fields – One Family's Experience of Raising a Child with Down syndrome.' If you would like to read the book, it can be borrowed from BCC libraries or purchased online from the publisher, www.bookpal.com.au/

I am going to refer to Down syndrome as DS for the duration of this presentation.

I am not accustomed to public speaking and am not qualified to address you in any role except as that of a parent with an adult son with DS so please bear with me as I share some of the pain and pleasure of raising a child with DS to adulthood, a task which is still ahead of some of you. If your family member has a condition other than DS, I hope that some of what I have to say will prove useful to you as well.

The transition from childhood to adult life is a challenging time for individuals and parents under any circumstances but, in my experience as the mother of three sons, it is a little more complicated when the child has DS. In our case, the transition started earlier and lasted longer with Steven than with our other sons; in fact, at 36, Steven still finds new ways to challenge us almost daily, boundary-testing somewhat in the manner of someone in their early teens. Maybe Steven still experiences some teenage-type growing pains and it catches us by surprise to realise that our thirty- something son is still working his way through these.

The transition to adulthood for young people with DS is complicated by the necessity, as a parent, to provide additional assistance to ensure that h/she can maximise their potential by having access to extra resources. Clearly, our non-DS children are likely to be better equipped to make choices, look for options and find the ways to explore those options than those with DS. In my experience, parents sometimes need to be confident to speak up, question decisions and sometimes demand a fair go on behalf of their DS child. Fortunately, things have improved considerably in the years since I had to fight for privileges for Steven that were readily available to my other children, for example, his inclusion in a regular pre-school (which we did achieve). But I have always deeply regretted our capitulation, after a long fight, in settling for a 'special school' because the resources that would facilitate his inclusion in a regular school were not available in the early 1980's. As a result, Steven did not receive much formal education with the principal emphasis at special schools of the day being on 'life skills'. If Steven were at school now, I would certainly be advocating for a much more formal education with emphasis on reading, writing, maths and other regular subjects.

However, despite his lack of formal education, Steven has a job he loves. He works as an Assistant Groundsman at a local private college, a job which he has held for over seventeen years since leaving school at the end of 1995. The arrangement is called 'supported open employment' and is a three-way deal between the College, the Uniting Church and Steven (with us on the periphery). The school employs four men with disabilities on a single wage and the church employs a supervisor who works with them. A part disability pension makes their pay up to a living wage. Steven works full time, a forty hour week, so he has something important to do every day (he gets only four weeks holiday a year, not school holidays) and he is a well respected member of the team. He enjoys his holidays but, while he's away from work, worries about whether his jobs are being done properly or whether someone else is using his tools. We have needed (and have been very willing) to provide support to Steven and, on occasion, to the other parties in this arrangement over the years. The partnership has not been without its hurdles but frank discussion (and sometimes strong advocacy on my part) has always paved the way to a resolution of the issues that have arisen. This job is a dream come true for us all and the College is a hugely important part of Steven's life. The only drawback is the cap on the supported wage which does rather compromise the integrity of the supported wage system as this caps Steven's earning potential to his share of the wage entitlement (25%). I admit this does bug me a bit but I still have my thinking cap on. I'm always wary of rocking the boat so accept things as they are for now; however, there may be a way to obtain a fairer result for Steven and the other workers in the future

I am certainly not qualified to discuss health issues, for that you need a really understanding GP (in my opinion there is nothing wrong with doctor-shopping until you find one) and access to a range of specialists. However, in the transition to adulthood for my son, some of the issues that demanded attention were: controlling weight, checking thyroid function, dealing with skin disorders (this continues), regular checks on bone density, cardiac issues, sexuality, self-esteem and of course the dental, sight and hearing issues that we all need to check on regularly. So, health monitoring is vital and in my opinion the best GP you can find is the place to start, closely followed by regular contact with QCIDD. Always remember the QCIDD Comprehensive Health Assessment Program (or CHAP), this program may prove very useful if, for any reason in the future, you are unable to manage your family member's health care.

In relation to sexuality, I guess as parents it is difficult for us to accept that, for our DS kids, sexuality, desire and attraction is normal, expected and okay. Perhaps it makes us uncomfortable because it is necessary to have more (and more detailed) discussions than we do with our other children on this topic. We can accept that the others are fully informed about their decisions and fully equipped to deal with the consequences (ie. love, lust, break-ups, marriages, kids etc.) but it is necessary to have more input into sex education for our DS kids and we are not all equipped to do it well. Help is available (Family Planning Queensland is one option) but, whether you seek help or not, one of the ways that we can develop resilience and capacity for a full life is with basic sex education. This creates safeguards and allows for healthy and positive attitudes to sex and sexuality.

Other issues that have to be considered at this transitional time are: independence, employment, accommodation, recreation, financial resources and friendships. For our family, the hardest of those has proved to be the latter.

Steven is now as independent as we can make him, has a full-time job he loves, his own home (I'll tell you about the battle with the bank at the end of this presentation if time permits), financial security and limited recreational options.

Providing him with friends of his own age who like him for who he is and because he shares similar interests is the ongoing challenge of our lives. We have tried many social and church groups; all have started off well but inevitably the novelty has worn off after a few weeks. This is frustrating because Steven is a sociable, friendly man with good social skills and an overwhelming desire to be like everyone else. He'd love to have a couple of mates over for a game of pool or go to the car-racing or a rock show with, the sort of things that, had he not scored that pesky extra chromosome, he would have been doing like everyone else.

We have always downplayed Steven's disability and made a great deal of his many abilities and now, as he approaches middle age, he has become a little unrealistic about those abilities (or perhaps he is just over-confident like many men of his age). Sometimes, issues have arisen which have taken a lot of time to unravel and resolve. I have been required to make many apologetic explanatory phone calls simply because Steven has attempted to deal with some issue himself, not recognising (or not wanting to admit) that he was in need of support. I'll give you a fairly harmless recent example. I suggested that I might change hairdressers as a home-based salon had opened in our street.

Stubbornness is a trait in our family. Steven has two parents who have trouble admitting they might be wrong (naturally his father is much worse than me) but it does seem that one of the traits of DS is often stubbornness so I guess he has scored a triple dose of that gene. Unfortunately, his apparent inability to co-operate has sometimes seen him miss out on opportunities that have presented themselves. I'd like to share an example with you from my book, it's from when Steven was fourteen but it's a good example of how, then and now, Steven's stubbornness inconveniences people other than himself.

Steven does not read well enough to be able to handle his own mail but, if he beats me to the mailbox and there is a letter addressed to him, he is likely to put it away without showing it to us because it is 'his' mail. There have been a number of occasions when this has meant that he has missed important appointments so I have now arranged for important mail to be duplicated and a copy sent to me from the bank, Centrelink, his employer and the many health professionals we have dealings with. This works well as Steven gets to keep his mail and I still know what's going on. We have applied for some funding through the Community Living Initiative and, if successful, some of this funding will be used for literacy and numeracy training. It's probably unlikely that Steven will reach a level of literacy and numeracy that will enable him to operate confidently in today's increasingly complex world; however, if not, the ability to read and write at a higher level than at present can only enhance his life.

I'm pretty big on human dignity, it is a passion of mine to ensure that I 'do unto others' and I hope I have brought my children up to believe in the fairness of a fair go for everyone. I honestly believe that Steven, and every other person alive, with or without a disability is entitled to pursue a life that is challenging, stimulating and worthwhile. Why should anyone be forced, due to circumstances completely outside their control to settle for second or third best and in some cases, settle for nothing at all?

I wish you all the best with your efforts on behalf of your family member and of course your other children as well. I have now reached the stage of grandparenthood, having six grandchildren ranging in age from five to twelve years. I love them dearly but admit that I would not like the task of raising children in the age of the Internet, social networking and reality TV. So ...good luck with the task ahead which is indisputably the most important one you will ever do.

Finally, when you feel tempted to throw in the towel, try to remember this; ultimately, throwing in the towel just makes more laundry!

www.bookpal.com.au/