



May 2008

Vol1 Issue 1

## Accreditation

We made it through our first accreditation under the Disability Services standards. IHCA (Institute for Healthy Communities Australia) undertook the review in March and the report was delivered in early April. Several service users of clinical services were involved in giving their feedback. We have established a Quality Team which is overseeing our continuous improvement. We are also establishing a QCIDD advisory group to provide feedback on our services.



INSTITUTE FOR HEALTHY COMMUNITIES  
AUSTRALIA LTD.

## Planning, expanding, changing



2008 is full of new ideas and plans for the future of QCIDD, both in terms of research and clinical services. We are hoping to have two psychiatric registrars join our clinical team in the latter part of the year. As well, we hope that we will be able to get another GP on board to meet the constant demand for clinical services. Our research team has big ideas for expanding our current research programme. Because the research of QCIDD is unique, we hope to keep surging forward to improve the health and well-being of people with intellectual disability. We had an organizational planning day in May 2008 and came out with very strong directions.

## Fragile X Clinics

Fragile X includes genetic conditions which can impact on individuals and families in various ways. Some people may experience significant challenges because of its effects while others experience only minor things which may never be diagnosed. Fragile X is more common than Down syndrome and cystic fibrosis. A person with Fragile X may experience speech delay, intellectual disability, and motor and coordination problems which can include epilepsy. People with Fragile X have their own personalities and strengths which can include a great sense of humour, excellent memory and great mimicry skills.

QCIDD is running its next Fragile X clinic on 21st November 2008. The clinic will provide a tertiary comprehensive health assessment service. This entails a thorough examination of all aspects of a person's health care: both physical and mental health. A referral from the person's GP will be required before the appointment. A pre-appointment questionnaire will be sent to all persons referred to the Clinic. To enquire further about the operation of the Fragile X clinics, please call Lisa on (07) 3163 2524. To book an appointment, please call (07) 3163 6102.

The FX Clinic is located at QCIDD  
Co-located at Kids in Mind Private Clinic  
Level 5, Mater Private Hospital  
Annerley Road Campus  
41 Annerley Road, South Brisbane QLD 4101  
Referrals can be faxed to the clinic on  
(07) 3163 6122.

A small number of families affected by Fragile X are keen to set up a Queensland based support network. Interested individuals or families who may wish to participate in planning this support group or network should contact Lisa on  
07-3163 2524.



## University Of Queensland

### QCIDD

University of Queensland  
Mater Hospital  
South Brisbane Q 4101

Phone: 61-7-31632412

Fax: 61-7-31632445

E-mail: qcidd@uq.edu.au

For Adults with Intellectual  
Disability  
Research, Education, Advocacy  
and Clinical Services

QCIDD aims to improve the health and well being of Queensland adults with intellectual and developmental disabilities through:

- clinical practice
- education, and
- research

QCIDD provides clinical services at no cost to adults with **intellectual or developmental disability** who are 17 years and older.

QCIDD's clinical service is not intended to replace your general practitioner. Instead our service provides a comprehensive health assessment, with referral back to your GP and others (for example, medical specialists or allied health professionals). The comprehensive health assessment entails a thorough examination of all aspects of a person's health care: both physical and mental health. It usually involves 3 one-hour appointments and further follow-up and review appointments as required.

Our doctors are general practitioners who have a special interest and expertise in the health care of people with intellectual disability. At the same time, they are not experts in every area and our clinical service is limited. As the QCIDD clinic is a small part of the overall work of QCIDD, we are only able to offer a limited number of clinic appointments each week and waiting lists can be quite lengthy.

### We can provide:

- Health assessment and review
- Advice regarding your health care
- Limited follow up as outpatient
- Support for primary health services such as your regular GP and other medical practitioners
- Referral and advice to assist you to link with other services and health professionals
- Advocacy in the healthcare system or advice about how to get the best from the health system
- Liaison with key support services Intensive Behaviour Support Teams.

### We cannot provide:

- 24 hour cover
- Emergency response or crisis intervention
- In-patient assessment (our doctors do not have admitting rights to hospital)
- Intensive follow-up
- IQ assessments
- Full functional or behavioural assessments by psychologist

## QCIDD goes bilingual



QCIDD has just published an article about sexual health of people with intellectual disability in the Mexican Journal of Public Health. Just recently, we gave our first presentation in Spanish about intellectual disability and the work of QCIDD to the Seventh Day Adventist Church. We are keen to continue publishing in Spanish which is now the second most commonly spoken language in the world. Recent links with the Pan American Health Organization PAHO may well cement our relationship with the Spanish-speaking world.



## Working with the World Health Organisation

In June 2007, Associate Professor Lennox was approached by the World Health Organization (WHO) to be the lead author on a chapter in the upcoming *World Report on Disability and Rehabilitation*. A/Professor Lennox and Miriam Taylor are leading their contributing authors in writing a section of a chapter on Mainstream Health Interventions (for all disabilities in all countries) for this report.

*The First World  
Report on  
Disability and  
Health will be  
released in  
September 2008  
and QCIDD is  
part of it!*

Dr Lennox's contributing authors to the World Report include:

- Professor Fabricio Balcazar, University of Illinois Chicago, USA
- Professor Lisa Iezzoni, Harvard Medical School, Boston, USA
- Dr Michele Foster, University of Queensland, Australia
- Associate Professor Jennifer Jelsma, University of Cape Town, South Africa
- Associate Professor Robert Kohn, Brown University, Illinois, USA

## Learning more about Facilitated Communication

Matthew Wilson, Senior Speech Pathologist from Disability Services Queensland came in March to talk about his long experience in assisted communication for people with high support needs.



## Latest Presentations

Dr Madonna Tucker has been running the *Challenging Behaviour Mentoring Programme* this year. In April, she also presented at the Halwyn Centre discussing QCIDD and the services provided. Additionally, Dr Tucker continues her close work with Disability Services Queensland in training around challenging behaviour issues.

Our staff continue the teaching programme at the *University of Queensland* in the medical, psychiatric, nursing, social work and occupational therapy undergraduate programs. This year Dr Lisa Bridle presented to students at the *Queensland University of Technology* in Disability and Human Services.

Our focus on providing information to community based services continues with Dr Lisa Bridle talking at the *Kyabra Future Accommodation Expo*, and Lyn McPherson and Miriam Taylor speaking to *Westcare*.

## Meet our staff

QCIDD is proud of its staff who have so many skills, backgrounds

### Dr Nicholas Lennox (Associate Professor and Director)



Nick is a *researcher, educator, advocate and clinician*. He has specialised in the health of adults with intellectual disability since 1992. He trained in general practice and also for a time in psychiatry.

He has developed several interventions to improve the health of people with intellectual disability. They include the CHAP (Comprehensive Health Assessment Program) review; the *Ask* health diary; the first whole of life handbook on health people with intellectual disability; a dual diagnosis educational kit, and a website and book on how to

manage Diabetes.

He has been instrumental in the IASSID (International Association for the Scientific Study of Intellectual Disability) ratification of health guidelines and has successfully advocated for systemic change at local, state, national and international level. This includes the adoption of the CHAP health review process by most state governments and many NGOs across Australia and overseas. He has also been instrumental with others in the successfully advocating for of a health assessment Medicare payment system to support GPs to perform these assessments on people with intellectual disability. He is the current President of the Australian Association of Developmental Disability Medicine (AADDM). Dr. Lennox has published widely in national and international journals.

Nick is the father of four and a keen cyclist.



**Dell  
Hele**

Dell is the full-time personal assistant to Dr Lennox. She has been with QCIDD since 1999 in various administrative support positions for projects including DSQ CHAP study, Dual Diagnosis Education, Training and Needs Analysis and PAS-ADD. Dell also contributes to the Quality Team and keeps us going with her delicious cakes! Dell is a mother of two.

### Ros Murrell



Ros is key to the Clinical Services Team. She has been with QCIDD for more than 6 years on various projects including Advocacy and Health, Endeavour CHAP Study and Diabetes. She is the mother of two, grandmother of two and an Italophile having spent many years in Italy.

### Dr Lisa Bridle



Lisa is Clinical Coordinator of QCIDD. This role includes providing phone/email consultation on QCIDD's clinical service and linking people to other appropriate supports. Lisa has been very involved in the development of QCIDD's quality systems and accreditation.

Lisa has worked in a variety of social work positions, including community development, counselling, domestic violence support work, community education and university teaching. Lisa is the mother of three children and since the birth of her son, Sean, she has been an active member of a number of disability support and advocacy organisations, including the Down Syndrome Association of Queensland. Lisa's research interests include: disability bioethics (particularly the ethics of prenatal diagnosis) and family experiences of disability and models of family support. Lisa is passionate about working to build a community where people with disability would routinely find welcome, and where their gifts and contributions would be justly recognised.



## Lyn McPherson

Lyn came to QCIDD from the University of Queensland Cancer Prevention Research Centre with a background in librarianship and public health. She is the manager of the Ask Project which is funded by the NH&MRC for five years. Lyn is the mother of two.

The Ask Project currently has three talented part-time research assistants, Sandi Meibusch, Julianne Yates and Lorraine Connelly.



## Dr Madonna Tucker

Madonna is a psychologist, member of the Clinical team, and the initiator of the Challenging Behaviour Mentoring Programme. She is actively involved in the teaching programmes. Madonna is mother of two.



## Dr Gillian Eastgate

Gillian has particular interests in intellectual disability, sexual health, family planning, indigenous health, alcohol and drug medicine, and teaching (Medical students and General Practice Registrars). At QCIDD she does clinical work and has written several educational articles for Australian Family Physician. She is also a contributing author to "Management Guidelines: People with Developmental & Intellectual Disabilities". Gill is the mother of two.

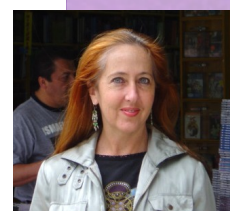


## Dr Robert Craig

Robert provides clinical services on a Friday and has trained in psychiatry. He maintains a keen interest in literature and the arts. Robert is the father of four.

## Miriam Taylor

Miriam re-joined QCIDD in November 2007 after 5 years in Colombia, South America. Miriam is a researcher of and advocate for the betterment of health and well-being of people with intellectual disability with special emphases on sexuality and the right to bodily integrity. Miriam is the mother of one daughter.



## **Challenging Behaviour Mentoring Programme**

This programme is supported by the Strengthening Non-Government Organisations Organisational Planning Initiative of Disability Services Queensland. The programme works with support staff of non-government service providers in Queensland. It has been running since late 2007 and will continue until December 2008.

The programme provides support staff with a mentor to increase their knowledge and skills in positive behaviour support and provides support to organisations to increase their networks in positive behaviour support.

The programme has been running very well this year with a number of support staff from across Queensland participating. We have staff from areas such as Townsville, Cairns, Mackay, Toowoomba and Brisbane.

So far, the staff of the programme have been involved in a two day workshop looking at positive behaviour support issues which ran in February of this year. They have also been receiving educational self-paced resources in the form of learning modules every month, to examine in detail topics relating to positive behaviour support.

Some of the feedback we have received so far about the programme from staff has been very positive and includes comments such as: “really interesting” “really beneficial and very exciting”; “everything set out really well and in plain English”.

All of the participants will meet on the 2<sup>nd</sup> and 3<sup>rd</sup> of June for the second set of workshops where they will be learning about choice making, restrictive practices, augmentative communication and reinforcement schedules amongst other topics.



## **The Ask Project**

The official title of the project is “RCT of an Intervention to Improve the Health of Adolescents with Intellectual Disability”. It is NH&MRC funded and will last five years.

The project objectives are to implement and evaluate the effectiveness of a combined education and health intervention package for adolescents with intellectual disability in South-East Queensland:

An education component—the *Ask (Advocacy Skills Kit) Health Diary* is used by each adolescent to collect personal health information and to learn self-advocacy skills. This component of the intervention is school-based and taught as part of the adolescent’s regular education program. A *Curriculum Strategy Guide* that outlines lesson plans and resources for teaching the *Ask Health Diary* curriculum was provided to the adolescent’s teachers.

A health component—a comprehensive health review (the *Comprehensive Health Assessment Program* or *CHAP*) performed on each adolescent by her/his general practitioner.

In brief, the project aims to determine: (1) if adolescents with intellectual disability using this package receive better health care (e.g., health screening) and improved health outcomes; (2) if using this package improves health advocacy by adolescents with intellectual disability and their parents in the context of visits to the general practitioner; and (3) if this package is acceptable to adolescents with intellectual disability, their families, their teachers, and their general practitioners. The *Ask Project* builds on an earlier QCIDD project conducted at the Darling Point Special School in 2004 (i.e., *Evaluation of the Health Advocacy Diary*).