

QCIDD PRESENTS

DR HENNY LANTMAN

PROFESSOR OF GENERAL PRACTICE, THE NETHERLANDS

**Towards inclusive health care for persons
with
intellectual disability**

**General practice based research on health and health care of
persons with intellectual disability in the Netherlands**

MONDAY 20 JULY 2009 From 1-2pm

**Corbett Room, Floor 1, Whitty Building, Mater Hospital,
South Brisbane**

This event is free.

Please RSVP via email or fax by Thursday 16th July

Phone: 3163 2412 Fax: 3163 2445 E-mail: qcidd@uq.edu.au

Contact - Miriam Taylor

Why are people with intellectual disabilities sicker than the general population?

Associate Professor Nicholas Lennox

The National Preventative Health Strategy (2008) recommended that Australia face up to its responsibilities with those who have the poorest health. There are over 300,000 Australians who have intellectual disabilities. Australian research clearly shows that for people with intellectual disabilities:

Only 29% of health conditions are being diagnosed and appropriately treated. 42% of health conditions are undiagnosed and half of the diagnosed conditions are inadequately managed. [1]

Obesity is up to three times the level in the general population. [2]

Dental disease is up to seven times more frequent than in the general population. [3]

42% of people who die in care are underweight and some die because of critical illnesses being untreated [4]

Life expectancy is much lower than the general population, and approximately twenty years lower for people with severe disabilities. [5]

Their poor health status arises from the interplay of various factors [1, 6-8]. Communication issues between professional and patient become problematic with the person's reduced capacity to communicate and the poor training of professionals in communication techniques. This population often have high rates and complex ranges of health problems, and some are at increased risk due to genetic syndromes. Health professionals need to spend more time with them but the health system often does not allow for this. Problems of diagnostic overlay occur wherein the symptoms are mistakenly related to the disability. They experience poverty and health promotion campaigns and research tend to ignore them.

Our centre has run the largest randomized controlled trials (RCTs) of preventive health assessments in people with intellectual disabilities in the world. Our health assessment, (CHAP) the Comprehensive Health Assessment Programme is a primary health tool which shows how prevention can work. It leads doctors to take action on improving hearing and vision, increasing immunizations, taking weight measurement, reviewing epilepsy and investigating constipation. In Australia, the CHAP is used in most states and the public health system, Medicare funded over 7,000 health assessments between July 2007 and May 2008. Alongside the growing international recognition of poor health outcomes for people with intellectual disabilities, our centre has shown that simple improvements in their health are possible, and that "good prevention works".

- (1.) Beange, H., A. McElduff, and W. Baker, *Medical disorders of adults with mental retardation: a population study*. American Journal of Mental Retardation, 1995. **99**(6): p. 595-604.
- (2.) Stewart, L., H. Beange, and D. McKerras, *A survey of dietary problems of adults with learning disabilities in the community*. Mental Handicap Research, 1994. **7**: p. 41-50.
- (3.) Scott, A., L. Marsh, and M.L. Stokes, *A survey of oral health in a population of adults with developmental disability: Comparison with a national oral health survey of the general population*. ADJ, 1989. **43**: p. 257-261.
- (4.) Torr, J., *The Psychiatry of Intellectual Disability*. 1999, Melbourne: University of Melbourne.
- (5.) New South Wales Community Services Commission, *Disability, death and the responsibility of care: A review of the characteristics and circumstances of 211 people with disabilities who died in care between 1991-1998 in NSW*. 2001, New South Wales Community Services Commission: Sydney.
- (6.) Bittles, A.H., et al., *The influence of intellectual disability on life expectancy*. The journals of gerontology. Series A, Biological sciences and medical sciences, 2002. **57**(7): p. 470-2.
- (7.) Emerson, E., *Underweight, obesity and exercise among adults with intellectual disabilities in supported accommodation in Northern England*. Journal of intellectual disability research JIDR, 2005. **49**(Pt 2): p. 134-43.
- (8.) Emerson, E., *Poverty and people with intellectual disabilities*. Mental Retardation and Developmental Disabilities Research Reviews, 2007. **13**: p. 107-113.

Fragile X Syndrome

BRIDGE TO BRISBANE

The Fragile X association of Australia (Queensland Branch) is looking to be part of the famous Bridge to Brisbane. We would like to get a fragile x team together to walk 5kms. If you're able to walk or run 5km's and you're free on the 30th of August, please register on the Bridge to Brisbane website from June 14. www.bridgetobrisbane.com.au

To raise money for Fragile X syndrome, please also register with www.everydayhero.com.au. Once you've registered with everyday hero, email your everyday hero details to all of your friends and family. This way all of your friends and family can donate online through everyday hero to the Fragile X Association of Australia. As you know, Fragile X Syndrome is a condition that is hardly heard about; participating in the Bridge to Brisbane will help to raise money about this very important cause, as well as spreading awareness of this condition.

Once you've registered, please email me your t-shirt size and I will organize a fragile x association of Australia t-shirt for you to wear at the Bridge to Brisbane.

Please feel free to phone or email me if you have any questions. I look forward to hearing from you!

Mel Mikkelsen mikkelsenfamily@optusnet.com.au 0411 018 641

“COMMUNICATION IN HOSPITAL: THE PATH TO BETTER HEALTH CARE”

DO YOU KNOW ANYONE WITH DEVELOPMENTAL DISABILITY WHO IS GOING TO HOSPITAL OR HAS BEEN IN HOSPITAL?

Over the next four years we are studying what communication in hospital is like for adults with developmental disability. We would like to interview people who have been a patient or cared for a patient with developmental disability in hospital (including paid carers and nurses in hospital). We would also like to observe patients with developmental disability in hospital while they communicate with others.

Where can I find out more about the project? Please contact Dr. Bronwyn Hemsley at the Communication Disability Centre, The University of Queensland on (07) 3365 2089 or email b.hemsley@uq.edu.au for an information sheet about the project and it will be sent to you.

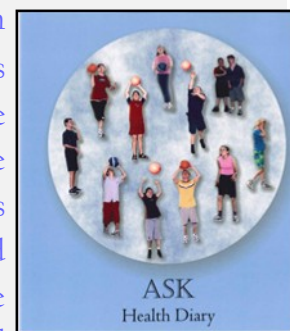
Dr Cathy Franklin—Psychiatrist

Cathy is our Consultant Psychiatrist. Cathy works at the QCIDD Clinic on Wednesday mornings providing assessments and management plans. To enquire about how to refer to Dr Franklin, please phone 3163 2524.



Establishing this position, with Dr Cathy Franklin conducting psychiatric assessments and management plans, has highlighted demand for ongoing follow up for a number of individuals whose needs are not currently being adequately met within the mental health or disability service systems.

The Ask Project In 2007 12 special schools and 26 special education units in south-east Queensland taught the Ask program to some of their students. This program based on the Ask Health Diary aims to increase the health advocacy skills of adolescents with an intellectual disability. On completion of the program, the diaries were sent home for families to use. Later that year parents or carers were asked to take the adolescent for a CHAP health review. These families, together with families from 35 other schools that did not teach the program, had previously completed a baseline survey for us. Now we are contacting them all again in order that we may evaluate the program. We are asking families about the diary – do you still have it? Have you used it? What you think about it? How do you think we could make it better? We are asking families about the CHAP – How did the appointment go? Were there any problems? Did you think it was a good thing to do? We are asking them other questions to see if there has been any improvement in the adolescents' self advocacy skills. Their answers to these and other questions will be compared with those of the families of participants who have not received the diary or done the CHAP. Once we have collected all our information, Ask diaries and CHAP booklets will be sent to families who have not received one as yet.



ASSID Qld State Conference



Walking the Talk: Improving Practice Regarding Complex Needs

Saturday 15 August 2009 9am~ 4:30pm

Queensland University of Technology (QUT),
Gardens Point Campus

Keynote Presenter: Professor Patricia Howlin

Professor of Clinical Child Psychology, Institute of Psychiatry, King's College London. Patricia has authored many publications in the field of autism and other developmental disorders and is a Plenary Keynote Speaker at the Asia Pacific Autism Conference in Sydney in 2009.

RSVP 7 August 2009

ASSID members \$140, Non members \$155

This conference will tackle current issues regarding autism and restrictive practices for adults and children with intellectual disabilities. Presentations will examine interventions and practices to allow better understanding of the complex needs of individuals.

Other key presenters include: Deb Keen (GU), Kate Sofranoff (UQ), Dianne Pendergast (Adult Guardian), Susan Gardiner (GAAT), Grazia Catalano (SRS), Lisa Fraser (Centacare), Nicholas Lennox (QCIDD), Stuart Kinner (Burnett Inst), Lisa Bridle (QCIDD), Janice Rushworth (SRS).

For more information contact Lyn McPherson on 3163 8267 or l.mcpherson@uq.edu.au
or Madonna Tucker on 3163 1983 or madonna.tucker@uq.edu.au

Recent presentations

April

Shepherd Community Services on Health issues for people with disabilities

May

Historical responses to people with disability and sexual expression

Social Work & Social Policy, Contested Nature of Health and Illness: Disability

June

Challenging Behaviour Mentoring Program

MBBS Year 1 lectures on Living with Disability at St Lucia and Ipswich University of Queensland campuses (photos below)



Recent attendances

May

CRU Review

Anne Donnellan and Martha Leary on Autism

June

Joint Forum with the Public Trustee, the Guardianship Tribunal and the Office of the Adult Guardian

Relationships and Sexuality Network – Carol Llewellyn Scorey on counselling techniques

Developing cross-disciplinary leadership capacity for enhancing the professional preparation of multidisciplinary mental health professionals

South West Disability network