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THE UNIVERSITY
OF QUEENSLAND

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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 Inaugural Educational Forum

29th November 2010

Our long history of education work was presented to representatives from the disability, tertiary education, advocacy and non-government sectors. We sought their ideas about directions for our education work in order to formulate our strategic plan.

Some of the ideas which came out of the day were:

- ☐ For QCIDD to advertise itself more widely;
- ☐ To raise awareness of our online resources;
- ☐ To run a workshop for people with intellectual disability, support workers, family members and general practitioners on how to use the CHAP;
- ☐ To develop a special interest group on ageing and end of life pathways;
- ☐ To increase awareness of people's communication needs in hospital and emergency staff;
- ☐ To extend our undergraduate teaching program beyond the University of Queensland to other universities.

We have already started working on some of the recommendations.

We aim to undertake similar targeted consultation forums for our research, advocacy and clinical services in the near future.

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 2011.

Merry Christmas

Feliz Navidad

Joyeux Noel

Froehliche Weihnachten

Buone Feste Natalizie

Maligayan Pasko

Nollaid Shona Dhuit

Summer Scholarships

QCIDD has offered summer scholarships again this year for students to undertake short research projects and to produce publications. Our summer scholarships of last year were greatly productive and we look forward to interesting results from our three summer scholarships for 2010-2011. This year we will have some financial support from the University of Queensland Office of Undergraduate Education.

We are lucky enough to have Rebecca Chan, a medical student from Notre Dame University in Sydney, to undertake analysis of the data coming out of the Living with Diabetes study about people with intellectual disability and diabetes. This Queensland study is being driven by the UQ School of Population Health (<http://www.lwds.org.au/index.html>) and QCIDD supported a survey question dedicated to people with intellectual disability.

Health Economics student from the University of Queensland, Tan Doan, is with us for ten weeks to use his expertise in examining existing data and comparing the health of people with intellectual disability in an institution with those who live in the community.

Medical student from the University of Queensland, Gloria Wong, is with us for six weeks and will examine, amongst other things, the impact on families of health issues for people with intellectual disability.

School of Population Health student, Jamie de Pauuw has been working to develop a short literature review of health advocacy.

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The report “*Where’s My 2 & 5*” by Advocacy for Inclusion provides a qualitative study of the nutrition and wellbeing of tenants of ACT disability group homes. The report identifies a lack of choice in the diets of people with disabilities, and points to a need for greater decision making for the tenants of disability group homes.

People with cognitive disabilities face increased health risks and a 20 year life expectancy gap compared to other Australians. Hypertension is largely undiagnosed but twice the level of the general population, obesity is up to three times that of the general population, and dental disease is up to seven times more frequent. These shocking statistics led Advocacy for Inclusion to examine the diet, level of choice in diet, and sense of wellbeing through a series of qualitative interviews. “*Where’s My 2 & 5*” is the result of several months spent talking to people with disabilities.

Advocacy for Inclusion had strong anecdotal evidence that people with disabilities are living on a very poor diet high in take away food, processed food and soft drink. This needed to be investigated before we could work out how to address the situation and overcome the life expectancy gap for this vulnerable group of Canberrans.

The study outcomes indicate that people with disabilities may have a reasonably healthy diet, but usually with no input into the planning or preparation of the meals they eat, and with little variety. Their sense of wellbeing is poor as a result.

People with disabilities are just eating what is put in front of them, with little control over it. Many would like a choice about what they eat, and what they buy at the shops, but are currently not included in these decisions or in any food preparation. Most participants in our study do not drink enough water, and they don’t have access to culturally appropriate food.

Advocacy for Inclusion’s Nutrition Project is now developing a course for people with disabilities living in group homes, in order to develop skills for planning and preparing healthy meals on a budget, and to speak up for themselves so that they have the choices that everyone else takes for granted. This project, funded by ACT Health, will run over the next two years and include training for support workers so that they are better able to support self advocacy in people with disabilities. There is currently a large shortfall in self advocacy training for people with disabilities and we are now working on identifying how to provide more self advocacy training to meet current demand.

improving life for people with disabilities

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Pacific Rim International Conference on Disabilities

"Humanity: Advancing Inclusion, Equality and Diversity"

April 18 & 19, 2011 • Honolulu, HI: Hawai'i Convention Center

2011 Call for Proposals is Now Open



We invite you to submit proposals to the [27th Pacific Rim International Conference on Disabilities](#). In the tradition of Pac Rim, the 2011 conference will visit [familiar themes](#) and explore new directions—[Exploration](#) and [Innovation](#). We are truly excited about 2011; we hope you will be too. Continue this extraordinary journey with us as we deepen our commitment to advancing inclusion, equality and diversity.

With over 16 topic areas, pre and post conference forums, including the [International Forum on the Rights of People with Disabilities](#), we anticipate a rich dialogue and an exchange of best practices, research, methodology, and advocacy initiatives. With your participation, this can happen.

Proposals are being accepted in all [formats](#). Submit yours today.

Registration is Now Open

If you are only able to attend one conference this year, choose Pac Rim 2011 in Honolulu. Traditionally this conference is one of the most exciting for presenters and attendees—providing a unique balance of cultures, and issues of local, national and international importance.

For more information please visit www.pacrim.hawaii.edu. Feel free to contact us if you have a question or want to share a good idea at prinfo@hawaii.edu or (808) 956-7539. In the meantime, stroll through our new Web site and read about our topic areas.

Inclusion in Human Movements



Thanks to Dr Sean Tweedy (pictured left), QCIDD now provides a yearly lecture to final year students in the School of Human Movements.

Sean has a keen interest in increasing the physical activity of people with disabilities and has been an accredited classifier in Paralympic Athletics for the last three Paralympic Games. Sean also runs the Adapted Physical Activity Program (APAP) which is a free program over twelve weeks to assist people with disability to increase their physical activity. For details, please contact Sean on seant@hms.uq.edu.au or via the School of Humans Movements on (07) 33636240.

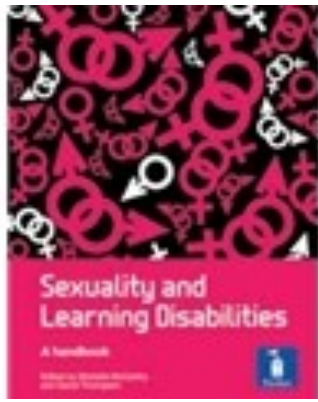
ASSID Conference a great success!

The 45th ASSID Conference was held in Brisbane in September/October and was attended by over 500 delegates from Australia, New Zealand, Egypt, Pakistan, Britain, USA amongst others.

Presentations can be viewed at the website:

<http://www.assid.org.au/ConferencePapers/tabid/59/Default.aspx>

There are papers for everyone there! It makes great reading!



Date: Thursday 3 February 2011

Venue: The Marino Centre, Griffith Avenue, Dublin 9

Intellectual disability and sexuality

Moving forward

The UN Convention on the Rights of Persons with Intellectual Disabilities has highlighted the need for equality and equal access to opportunities for cultivating personal relationships for people with intellectual disabilities. A great deal of research and forward strides are being made in all spheres of work in the area of sexuality and intellectual disability in Ireland. A key challenge facing people working in the area now is how to keep this momentum moving forward, and how to embrace and provide for the needs of 21st century Irish citizens with intellectual disabilities in all spheres of life.

This conference brings together a number of Irish and international experts in the field of intellectual disability who will discuss the past, present and future developments in sexuality and disability, and will face some of the taboos still present in sexuality and disability head on.

Key speakers

- **Zoe Hughes** *Social Worker and PhD Student, National Institute for Intellectual Disability*
- **Chair: Elzaan Goosen** *Chairperson, Connect People Network*
- **Frieda Finlay** *Chairperson, Inclusion Ireland*
- **Frieda Bent** *Instructor, KARE Services*
- **Edurne Garcia** and the Inclusive Research Network, *Researchers, National Institute for Intellectual Disability and the National Federation of Voluntary Bodies*
- **Jacqui Ashby** *BATIAS Stars in the Sky, UK*
- **Ann Lawlor and Aine Lawlor** *Mother and Daughter Team, 22Q11 Ireland*
- **CPN Peer Group** *(Connect People Network)*
- **Siobhan O'Doherty** *Researcher, National Institute for Intellectual Disability*

Who should attend?

It is hoped that this conference will attract a wide number of attendees, from service managers and frontline staff supporting people with intellectual disabilities, to family members and people with disabilities themselves. —People with intellectual disabilities; Family members; Policy makers; Researchers; Managers; Frontline staff; Sexual health service providers

To request a copy of the full conference programme email: louises@pavpub.com

Unable to attend this conference? Join us at '**Sexuality and people with learning disabilities**' on 6 April 2011 in London - email louises@pavpub.com for details.



RIP Anne McDonald, 1961 – 2010

Anne was an amazing woman who touched many peoples lives deeply - she had severe athetoid cerebral palsy and was institutionalised at the age of three. Many years later she came into contact with Rosemary, a new staff member who saw her intelligence and together they found a way to communicate via facilitated communication. With Rosemary & Chris she fought in the Supreme Court of Victoria to escape from the institu-

tion by proving that her communication was her own; then she had to fight to win the right to manage her own affairs and she fought for disability rights - and won all the battles. She got a degree, she co-authored a book which became an award winning film (*Annie's Coming Out*). Her tenacity was ferocious, she later wrote of her time in the institution: *Dying was dependent on the way you felt. Jobs in mental hospitals do not attract the best doctors, and there was no supervision. The patients could not complain. If you wanted to die you had every opportunity. Many short-stay kids took their chance. Death never appealed to me; I wanted revenge. Now that does not seem to matter. What is important is stopping other kids going through what we went through.* Anne had a great sense of humour, a love of reverse bungy jumping (she wrote that some recent trips to New Zealand were "officially to present at conferences, but really so I can go reverse bungy-jumping") and an addiction to anything to do with the Mona Lisa. I'll leave the last words to Anne, this is her acceptance speech from winning the Personal Achievement Award in the Australian 2008 National Disability Awards which she kindly gave me permission to reproduce. Vale, Anne, we will miss you. Our hearts go out to Chris & Rosemary.

Ladies and gentlemen,

I'd like to thank the judging panel for choosing me, and I'd also like to thank the many people who've helped me along the way and made it possible for me to be here in Parliament House tonight. I spent my childhood and adolescence in a state institution for severely disabled children. I was starved and neglected. A hundred and sixty of my friends died there. I am a survivor. That isn't a heroic achievement. Anyone who was put into a large institution in the times when large institutions were sugarcoated concentration camps was as much a hero as I was. They stayed alive when they could and they died when they couldn't. Such heroism is easy to achieve in giant barracks where the prisoners stay alive through being cheery enough to attract a staff member to give them that vital extra spoonful of food. I wasn't exceptional in anything other than my good luck. I was selected for an experiment. Rosemary Crossley wanted a subject for her Bachelor of Education literacy project. She chose me. The aim of the experiment was to see if I could make gains in my tight-armed pointing to blocks with different colours on them. Rosemary found I could point to colours, then to words, and then to letters. She taught me to spell and to make my wishes known. I made known my wish to leave the institution, and then all hell broke loose. I went to the Supreme Court and won the right to manage my own affairs. Unfortunately, that didn't mean that the institution offered the other residents the right to manage their own affairs. I was an exception. Through no desire of my own, I was out front in the struggle to get rights for people without speech. I tried to show the world that when people without speech were given the opportunity to participate in education we could succeed. I went to Deakin University and got myself a degree. That, too, was seen as an exception. I gave papers and wrote articles on the right to communicate. I set up a website to show that there was hope for people without speech. People thanked me for being an inspiration; however, they didn't understand why there weren't more like me. They continued to act as if speech was the same thing as intelligence, and to pretend that you can tell a person's capacity by whether or not they can speak.

Please listen to me now. The worst thing about being an inspiration is that you have to be perfect. I am a normal person with only normal courage. Some people who should know better have tried to give me a halo. Anybody could have done what I have done if they too had been taken out of hell as I was. If you let other people without speech be helped as I was helped they will say more than I can say. They will tell you that the humanity we share is not dependent on speech. They will tell you that the power of literacy lies within us all. They will tell you that I am not an exception, only a bad example. Many are left behind. We still neglect people without speech. We still leave them without a means of communication. It should be impossible to miss out on literacy training, but thousands of Australians still do. As Stephen Jay Gould wrote: "We pass through this world but once. Few tragedies can be more extensive than the stunting of a life, few injustices deeper than the denial of an opportunity to strive or even to hope, by a limit imposed from without, but falsely identified as lying within."

Frank Hall-Bentick
www.hallbentick.net

Chris Samuel
http://twitter.com/chris_bloke

Significant health gap between Australians with and without disabilities

Almost half of Australians with severe or profound disability are not in good health, according to a report released today by the Australian Institute of Health and Welfare. The report, *Health of Australians with disability: health status and risk factors*, found that 46% of Australians aged 15-64 years with a severe or profound disability reported poor or fair health, compared to only 5% of those without disability. People in this group had higher rates of all types of long-term health conditions than those without a disability. People with severe or profound disability were more likely to have acquired a long-term health condition earlier in life than those without disability. Some of these conditions were diabetes/high blood sugar level before the age of 25, arthritis before the age of 25 years and osteoporosis before the age of 45 years.

REPORT

2010 Publications

- Bridle L. **Challenges to the Human Rights of Persons with Intellectual Disability**. 2010
- Craig RD. **Timing of transfer for pregnant women from Queensland Cape York communities to Cairns for birthing**. Medical Journal of Australia. 2010;192(4):239.
- Lennox N, Bain C, Rey-Conde T, Taylor M, Boyle FM, Purdie DM, et al. **Cluster randomized-controlled trial of interventions to improve health for adults with intellectual disability who live in private dwellings**. Journal of Applied Research in Intellectual Disabilities. 2010;23(4):303-11.
- Lennox NG, Simpson JC. **Invisible People?** Medical Journal of Australia. [Letter to the Editor]. 2010 2 August;193(3):185.
- Mophosho M, Widdows J, Taylor Gomez M. **Relationships between adolescent children and their siblings with cerebral palsy: A pilot study**. Journal on Developmental Disabilities. 2010;15(3):81-7.
- Noonan A, Taylor Gomez M. **Who's missing? Awareness of lesbian, gay, bisexual and transgender people with intellectual disability**. Sexuality and Disability. 2010;DOI: 10.1007/s11195-010-9175-3.
- Taylor Gomez M. **Hysterectomy will not solve the problem: Response to "In that case"**. Journal of Bioethical Enquiry. 2010 22 September 2010;DOI 10.1007/s11673-010-9252-4.
- Brolan C, Ware RS, Lennox NG, Taylor Gomez M, Kay M, Hill PS. **Invisible populations: parallels between the health of people with intellectual disability and people of a refugee background**. Australian Journal of Primary Health in press.
- Lennox NG, Ware RS, Bain C, Taylor Gomez M, Cooper SA. **Effects of health screening for adults with intellectual disability: A pooled analysis**. British Journal of General Practice. in press.

Contact QCIDD if you want a copy of any of these.....qcidd@uq.edu.au

OUR LATEST COLLABORATIONS

- Queensland Advocacy Inc.
- Community Resource Unit
- School of Human Movements
- Professor Sylvia Rodger, School of Health and Rehabilitation Sciences, Occupational Therapy
- Julie Simpson, Parent2Parent

Wasted Lives Forum

QAI continues to be concerned about the many people with disability who remain living in institutional care in Queensland Health facilities. The Wasted Lives Campaign has been bringing issues relating to their lives to public attention through a series of issues papers and discussions with stakeholders, in an attempt to influence better lives on their behalf. For further information on the campaign, please contact QAI via their website:

www.qai.org.au