THE EMPOWERMENT COUNCIL 25th ANNIVERSARY 04 18 2018



EMPOWERMENT COUNCIL

Acknowledging the First Nations land we stand on

The Centre for Addiction and Mental Health (CAMH) has the honour of being situated on lands that have been occupied by First Nations for millennia. Toronto and its surrounding areas are the traditional territories of the ancient St. Lawrence Iroquoians, the Huron Wendat Nation and the Seneca of the Haudenosaunee Confederacy. Today's land guardians are the Mississaugas of the New Credit First Nation, and this Queen Street site is the historical place of camping and holding Council for the Mississaugas.

As an organization within CAMH, the Empowerment Council supports the ongoing importance of recognizing, respecting and acknowledging the First Peoples land on whose traditional territory we work both with our client membership, and in our work with staff. The Empowerment Council is also committed to working in solidarity towards reconciliation in partnership with First Nations, Inuit and Métis.

WEDNESDAY APRIL 18 2018

AGENDA

Welcome

Opening Remarks: Han Dong, Member of Provincial Parliament Trinity-Spadina

Keynote - Dr. Amita Dhanda

"To Speak and to Listen; the Dialogic Road to Inclusion"

Questions for Keynote

Break

Panel Discussion

Empowerment & Engagement Means Power & Partnership



25 Years of Engagement & Advocacy

The struggle to recognize, and respect the voices and rights of people who use services has been a long road. While we are now in the midst of new legislative calls for patient engagement, the truth is that service users have been politically engaged and participating for many decades. Advocacy — being a voice for others, has been a fundamental facet to ensuring that our human rights are protected in any and all healthcare strategies or transformation. This is especially important in psychiatric facilities where people are at their most vulnerable and may not have anyone to support their interests or wishes.

The rise of patient controlled-patient councils in the early nineties was one way that the interests and concerns of patients were heard. The impetus for these councils began in the eighties and was preceded by many reports such as the Graham Report (and others) which called for more citizen participation. More importantly, by the mid-eighties public scrutiny over incidents of abuse, overuse of medication, restraints, and deaths of patients let to reviews and rethinking about medical control, and the need to foster spaces where patients could be better heard. During this era, psychiatric survivors / consumers pushed against the ubiquitous paternalism in the mental health care system and struggled for mental health reform. Community members, allies and disability organizations made presentations or deputations at public hearings on the need for support from psychiatric hospitals for the development of patient councils.

By the 1990's the government of Ontario encouraged psychiatric hospitals to dedicate a portion of their budget to independent patient councils run by and for service users. The council model was one with service user members, boards elected by their members, and staff hired by them that reported to their Board of Directors. The value was one of citizen accountability, in which council staff took their direction from service users, and reported to them.

The first patient council was established at Kingston psychiatric hospital followed by the second at what was then the Queen Street Mental Health Centre. The Queen Street Patient's Council was established in 1992. Soon, other patient

council were also formed across many provincial psychiatric hospitals which subsequently prompted the creation of the Ontario Association of Patient Councils in 1993 - a coordinated network of representatives from Patient Councils in psychiatric facilities. The Queen Street Patient Council carried on its work from 1992 until 1999. The Queen Street Patient Council under the pressure of the hospital's impending merger of its three sites (Donwood, Addiction Research Foundation and the Clarke Site) joined the merger toward CAMH and subsequently became what we now know as the Empowerment Council. With the support and guidance of David Reville & Associates, an Empowerment Report was developed during the time of the merger and in this report, recommendations for the development and mandate of The Empowerment Council. The report also included recommendations for a centre wide Bill of Client Rights. The Empowerment Council was officially incorporated in 2003 and the Bill of Client Rights was adopted by the CAMH Board in 2004 and serves as one of the best Bills on sharing information about patient's rights.

Over the years, The Empowerment Council's work has grown and evolved. We are a sought after organization for student placements, hopes for employment with our organisation, endless requests of our expertise for education initiatives and presentations to universities, conferences, stakeholders in the justice system, police services and service user initiatives. Our research portfolio has been slowly growing as well as our academic contributions in the fields of Mad Studies, Law, Social Work, Medicine, Healthy Equity and Social Justice Studies. Our understanding about the importance of human rights for our most vulnerable citizens is well respected and recognized.

The model of patient engagement broadly followed in Ontario today involves advisory or focus groups instead of Councils, accountable to the hospital, as opposed to the community the hospital is there to serve. Now, Independent Councils thrive only in Penetanguishine and Toronto. The work of these Councils forms a continuity of advocacy work that is unparalleled in Canada and we need to continue to protect, support and empower the independent voice of service users for many years to come.

GUEST SPEAKERS



Amita Dhanda

Prof. Amita Dhanda is Professor of Law at National Academy of Legal Studies and Research, Hyderabad. She also heads the Centre for Disability Studies at the University. She has a substantive interest in the field of public law and human rights with special reference to disability rights. Prof. Dhanda's doctoral thesis critically appraising the laws relating to the mentally ill was a pioneering effort at evaluating the human rights conformity of mental health laws in the country. The thesis was later brought out as a book entitled "Legal Order and Mental Disorder".

This special research knowledge became the basis of the Supreme Court of India asking her to investigate and report on the condition of persons living with mental illness in the jails of West Bengal. The investigation resulted in the Supreme Court holding that the housing of persons with mental illness in jail was unconstitutional.

Her doctoral work got Prof. Dhanda to conclude that the social stigma of mental illness was reinforced by the law. Legal exclusion needs to be challenged and the legislative regimes providing for the incapacity and disqualification of persons with psychosocial and intellectual disability dismantled. This insight informed the work she did on legal capacity in the United Nations Ad Hoc Committee negotiating the Convention on the Rights of Persons with Disabilities.

Dr. Dhanda has been closely involved in the law reform work in her own country to formulate disability rights laws especially legal capacity and support regimes which are in conformity with the Convention on the Rights of Persons with Disabilities. Her expertise has been drawn upon by civil society organizations of other countries to inform their law reform efforts.

Chris Higgins:

Chris is the Team Lead for the Provincial Forensic Program and the MOHLTC. He started as a front-line community mental health worker, was the executive director of a supportive housing agency in Toronto and the executive director of the Ontario Federation of Community Mental Health and Addiction programs. He was the founding instructor of the Humber College psychosocial rehabilitation program and served on the International PSR Association board for many years.



Brenda A. LeFrançois

Brenda A. LeFrançois is a full Professor at Memorial University of Newfoundland. Her teaching, scholarship and activism focus on children's psychiatrization, sanism and anti-sanist praxis, from mad studies, sociology of childhood and critical children's rights perspectives. She has edited and authored many books, special volumes and journal articles on these issues. Her most notable contributions include the anthology *Mad Matters* and edited volumes in *Children & Society* and *Intersectionalities*.



Zoë Dodd

Zoë Dodd is a co-founder and program coordinator with the Toronto Community Hep C Program, a program which offers access to Hep C Treatment for people who use drugs. She has worked for many years on issues of poverty and health primarily focused on people who use drugs in both front-line, advocacy and research roles. She is currently one of the organizers and coordinators of the Moss Park Overdose Prevention Site and a graduate student in Environmental Studies at York University exploring people's relationship to drug treatment. As a worker and as an activist, Zoë practices community development, popular education and harm reduction within a social justice framework.



Over the years, there have been many people whose work and support has contributed to the effectiveness and the impact of the Empowerment Council. Our sincere appreciation goes out to those individuals and organizations – a few of whom are listed below.

Current Empowerment Council Board of Directors: Sheldon LaPorte (Co-chair), Darlene Stimson (Co-chair), Catherine Bennett, Erin Claman, Lorne Donnelly, Francine Geraci, Danielle Landry, Sandra Petite, Veronica Snooks

Past Empowerment Council Board Chairs including Beamer Smith, Cathie Adams, Susan Gapka, Andrew Hudson, Kelly Lawless, Joanne O'Brecht, Danielle Waters; and other founding or long-time board members including Leo Anter, Alex Buxton, Linda Chamberlain, Shannon Hardie, Alex Buxton, David Crockford, Gregory Kim, Carole King, Alex McLarty, Leslie Miller, Steven Torresan, and Dorothy Sedore.

CAMH and U of T staff: Catherine Zahn, Jane Paterson, Rani Srivastava, Lori Spadorcia, Janet Mawhinney, Vicky Stergiopoulos, Mark Fefergrad, Priya Raju, Kenneth Fung, Lisa Anderman, Paul Garfinkel, Joannne Campbell, Betty Miller, Workman Arts. And our late friends: Julia Greenbaum and Diana Capponi.

Empowerment Council volunteers/former staff and project colleagues: Stef Mendolia, Diann Chea, Toby Samson, Jonathan Balazs, Lisa Walter, Chris Spencer, Helen Hook, Lauren Munro, Julia Devaney, Jessica Evans, Andrea Daley, Lori Ross, Kathryn Church, David Reville, Victor Willis, Jijian Voronka, Roy Bonadonna, Peggy-Gail DeHal-Gunraj, Heather McKee, Carole King, Jenna Reid, Tucker Gordon, Sarah Prowse, and David Wong.

The Mental Health Legal Committee, Marshal Swadron & Associates, Mercedes Perez, Alexander Procope, Kelley Bryan, ARCH Disability Law Centre, Tess Sheldon, Karen Spector, Mary Birdsell, Suzan Fraser, Ryan Fritsch, Anita Szigeti, LAMDA, Parkdale Community Legal Services. A special thanks to all our counsel who have worked tirelessly with us in our advocacy efforts and have assisted us over the years with advice, court and inquest proceedings.

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