



# THE EMPOWERMENT COUNCIL

A Voice for the Clients of the Centre for Addiction and Mental Health

## *Empowerment Council Activities: 2016/2017*

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### Mission Statement

The Empowerment Council is a voice for clients and ex-clients of mental health and addiction services, primarily of CAMH.

The Empowerment Council consists of mental health service users who assist in conducting system-wide advocacy on behalf of clients and ex-clients.

## ADVOCACY

### Highlighted Advocacy Issue: Seclusion and Coercion

Segregation in the Canadian Correctional System has been increasingly in the eye of the media and the Canadian public. Ashley Smith brought a human face to the despair that isolation visits on vulnerable people – and we are all vulnerable people. We are social beings, and cannot endure long periods of isolation without becoming suicidal, violent, or psychotic.

What garnered less attention is that Ashley received the same treatment in the mental health system as in the Correctional system (worse, in fact, as her bodily cavities were searched).

We, the clients’ voice, the advocates, the Board members and all the people at CAMH who care, must understand that seclusion is not better because it occurs in a place called a hospital instead of a place called a prison. In a room called South Pod where a client is locked in all alone, he is just as alone as in a room *called* a seclusion room. Suicide can end up seeming the only answer just the same.



*“One of the most common themes was that the patient voice representation provides a necessary ‘reality check’.”<sup>1</sup>*

If people are told they will be put in seclusion if they won't accept medication that is restraint, it is not an alternative to restraint.

We must strive to do better. There are so many people here who ARE trying to do their best, but it's not enough. It has to be everybody, and we have to be willing to make human connection every time. We, the Empowerment Council, do not want anyone to be hurt. But we believe that compassion creates a place to be that is safer for everyone. Unfortunately a few people can undo the good of many who are kinder. This is a problem that has to be addressed. It is true that any group of people will have some that are unkind – but what allows them to continue? That's the question we have to answer.

Jeffrey James died when mechanical restraints were used on him, but it is not enough to concentrate on their reduction. His death and subsequent Inquest did inspire a concerted effort in restraint reduction, but it is waning. We understand that the pressures for Safety can seem to operate at cross purposes. But we believe we all want each other's safety, and it is a mistake to try to step on each other to try to achieve it.

The EC has a number of concrete suggestions for progress, but would like to proceed by inviting everyone to renew their commitment to the aspirational goal of no restraint use at CAMH – chemical, mechanical or seclusion - and to join us to do everything we can to make that happen. This goal touches on many related concerns of clients that can be best encompassed by calling it relationships.

We need good relationships. In our conversations with clients, how staff related to them was their primary concern. It can be a positive place to start, but it is not simple. Or maybe it is; it's just become occluded. We invite you to read the EC newsletter attached to this report to get a sense of what clients are saying. (You may be touched to see that many clients expressed compassion for staff.)

Survivor research “emphasized the relational elements of support and service provision, such as empathy, listening, and being treated with respect, as tantamount.”<sup>3</sup>

There is a concept in some social change circles these days, of calling people *in* instead of calling them *out*. We call you in.



“Voice” differs from participation in being more overtly autonomous. “Voice” contains the meaning of being heard but does not prescribe how or where. It presupposes organization, and contains the idea of collectivity and identity.<sup>2</sup>

## Advocacy Issues Raised in Various Forums at CAMH

- Advocacy to acknowledge South Pod as seclusion and people secluded within therefore deserving both legal and CAMH policy protections that apply to seclusion
- Praise for spread of value of trauma informed care. Still huge unmet need for trauma specific care - counseling
- Counseling/psychotherapy is constant client identified need by clients who are civil and forensic, inpatient and outpatient, waiting to become clients and discharged clients
- Worse than long waiting lists are closed waiting lists – and this creates errors in counting, as numbers do not reflect people waiting to get on waiting list
- Similar concern over what is counted – note that accessing an assessment is very rarely “access” from client perspective, who want actual help. When measuring, access should not be checked off if client needs are not met
- Need to meet the legal requirements of informed consent (everywhere in health care)
- EC advocated for a long time for need for evening and weekend activities for mental health and addiction clients, and is very pleased there are some. But there are still many clients without.
- Daily need for access to fresh air and/or exercise. Every inpatient unit should have at least a treadmill and exercise bike as a means of relieving stress when confined to floor. (Staff have a new wellness centre which is nice, but they could access it elsewhere.)
- Lack of Privacy available for staff to talk to clients on phone in Addictions (the predicted problem resulting from work stations having replaced offices)
- Surveying of CAMH clients has never been based on what clients identify as most important to them, so vital information is excluded. EC has pointed this out every year.
- EC has supported White Squirrel Way clients expressing concern about upcoming limitations to addiction care and aftercare.
- EC recognizes CAMH is under constant pressure to serve more people. We encourage CAMH to draw a line around a level of service that should not be further reduced in an attempt to serve more and more people.

## EC in the Media:

- “Coroner’s Inquest System” and “How one man’s tortured path led to stabbing rampage” in Toronto Star
- CBC radio Metro morning on public trust of police “Rise in lethal shootings of the mentally ill by police in North America”
- EC in Hold Your Fire - Documentary on CBC about policing and mental health (and reruns)



## Advocating for CAMH Clients at CAMH:

### Representing Clients on CAMH Committees

- CAMH Provincial Advisory: picking up the PACE
- Clinical Quality Committee of CAMH Board
- Fiscal Advisory Committee
- CAMH AGM
- CAMH Constituency Council
- Constituency Council Task Force
- Clinical Care Committee (CCC)
- CCC Subcommittees: Pornography, Privacy, Emergency Use of Restraints, South Pod, Protective Devices, Personal Electronic Devices, Client/Family Honouraria, CAMH Visitors, Aboriginal Policy
- Liaison (CAMH/FE/EC) Committee
- Prevention/Management of Aggressive Behaviour Revised (PMABR) Committee
- PMABR Implementation Committee
- Education Council
- Education Scholarship

In the U.S. there was a positive correlation between the extent of client empowerment through states’ statutes and the quality of mental health services.<sup>4</sup>



- Community Advisory Committee on Research (CACR)
- CAMH grant committee for community based research Fellowship
- Redevelopment meetings – on Reference Centre, common areas, EC
- Physician Assisted Death Working Group of CAMH
- Safewards Steering Committee
- Discharge Planning Committee
- Restraint Reduction Working Group
- Prevention of Restraints Committee – subcommittees on pamphlets
- Advocacy Coordinating Committee founded with Client Relations and PPAO
- Pending: Complex Care Council

## FOCUS GROUPS/CONSULTATIONS/OUTREACH TO CLIENTS

- *EC AGM, and mental health and addiction client nominating meetings, where clients of CAMH discuss their priorities, direct, and elect EC Board members*

### Client Consultations organized by EC for CAMH:

- Discharge Planning Client Focus Group
- PMABR: Prevention and Management of Aggressive Behaviour Revised consult on curriculum and implementation
- CAMH staff attending EC Board meeting to discuss Continuous Observation policy and practice (“observed” that watching someone not of much value to client, interacting in positive way is)
- CAMH staff attending EC Board meeting to discuss Passes and Privileges documentation (client view that rights are not privileges, succeeded in name change to just passes)
- Public Policy CAMH meeting to discuss areas of mutual interest
- Public Policy discussion about positions on Basic Annual Income – feedback on client perceived advantages and cautions
- Consult by Slight Centre for First Episode Psychosis – feedback on need to measure what is important to clients, which can differ from service provider priorities

- Consult on Client Transportation Policy (How does Restraint Policy not apply when people are in motion?)
- CAMH Digital Strategy
- Consult with clients, resulted channeled back to CCC. Policies on: Personal Electronic Devices, Client and Family Honouraria, Cannabis, Code Yellow, Protective Devices, South Pod
- Informational as decisions made - CAMH to addiction clients on changes to Addiction Program
- Surveyed clients on General Psychiatry Unit and forensic units 3-1, 3-3, 3-5 for Safe Wards

### **Other Expressions of the Client Voice at CAMH:**

- EC on Hiring Committees: Employment Works, Safe Wards Peer Worker and Peer Researcher, Client Relations
- Advocated for reasonable compensation for peer for Safe Wards Project
- EC on panel following Rendezvous with Madness film, co-sponsored other RM film
- EC consulted on use of video observation system at CAMH
- CAMH BLOG How do mental health clients feel about Physician Assisted Death?
- Consult by Workman Arts - Language and Appropriation
- Consult by CAMH HR on Development of Staff Wellness Centre
- Advocated for clients on issues of concerns raised at community meetings on General Psychiatry Unit and forensic units 3-1, 3-3, 3-5 on two occasions
- Feedback to Initiative on Patient, Caregiver and Public Engagement
- Focus Group “YOU MATTER! YOUR BODY MATTERS! Sex, Love, Relationships, Bodies & Access to Services A workshop for women (Women includes trans, cis-gendered and two spirit identified)
- Forum: “Medical Assistance in Dying: Where is the Client Voice?” Empowerment Council and CAMH June 2016
- Social Media Site Development : Medical Assistance in Dying for and by mental health service users <https://mentalhealthandassisteddeath.wordpress.com/>



## Advocating for CAMH Clients Outside of CAMH

### Work with Various Community Partners:

- Member of expert panel of Registered Nurses of Ontario (RNAO) creating Best Practice Guidelines on Crisis Intervention. Member of two working groups. Located content expert reviewer for RNAO draft Crisis Intervention Guidelines
- On City of Toronto Safe City Committee
- Curriculum Competency Committee of the University of Toronto, Department of Psychiatry
- Assisted Health Quality Ontario (HQO) on several consultations – where to find people to interview, rewrote posters to attract greater variety of people (they were very interested and appreciative of difference from their style of postering)
- Consulted by HQO on patient reference guides, how to survey on access to psychotherapy, how to survey people with experience of psychosis
- EC member of Ontario Association of Patient Councils EC ED Vice Chair
- PPAO Service Model Review Consultation and Feedback Request and Survey Dissemination
- Settlement of suit with Information Privacy Office re border
- Meeting with Psychiatric Patient Advocate Office for Update on PPAO Strategic Directions
- Quality Improvement Initiative (Dr. Paul Bernassi) Inquiry About Tobacco Use At Triage
- Legal Aid Ontario - Patient Legal Needs And Satisfaction Survey
- Connecting GTA Data Contribution Phase of the Connecting GTA Initiative
- Meeting with Family Outreach and Response
- *“A Place to Call Our Own”* – Supporting Access to Housing for Marginalized Women with Status of Women Canada
- Consulted for Strategic Planning of Ontario Human Rights Commission
- Legal Aid Ontario Mental Health Law Advisory Committee
- Consultation on the future of A-Way, a consumer/survivor initiative
- Teleconference National Network for Mental Health
- Department of Psychiatry University of Toronto - Competency Steering Committee meeting

- PSSP's Lived Experience Consultation Process
- Dept. of Psychiatry Sofia Pakula Social Justice Award Selection Committee
- Toronto LHIN: co-wrote report “*Consults, Feedback and the Future of Service User Inclusion in System Planning*”

## Courts

- *Stewart v Elk Valley Coal Corporation*, Intervenor status in case before Supreme Court of Canada, EC jointly with Council of Canadians with Disabilities (Duty to accommodate and right to privacy for people with addiction/substance use issues) Affidavit and Motion of Record submitted. Given time to address SCC. Awaiting judgment.
- Reviewing materials re. *Thompson and Empowerment Council v Ontario*; Lost at provincial level, EC decision not to appeal this case beyond Ontario (case about CTO's and Box B criteria).

## Advocacy with government

- Support for Bill 16 Amending Canadian Human Rights Act to protect gender identity and expression
- Joint submission by EC and CAMH to federal government on *National Housing Strategy*
- Joint submission by EC and CAMH on *Strategy for a Safer Ontario* to MCSCS
- Meeting with Councilor Michael Layton regarding discriminatory practice of Ward 19 business
- Support for Naloxone to treat opioid overdoses being available without subscription, anonymously and for no cost

## Advocacy related to Policing, regarding:

*people with mental health issues and other community members (primarily black community)*

- Toronto Police Service (TPS) Police and Community Engagement Review (PACER) External Advisory Committee - primarily ethnoracial community committee and advocates looking at the practices of TPS such as “carding” and racial profiling. EC only connection with mental health concerns. Influenced Ministry of Community Safety and Corrections Services CSCS changes to regulations on “carding” or “street checks”, as well as TPS Board and Chief’s regulations and procedures which extend further protections in Toronto (e.g. information to community members). Committee developed card TPS has to give member of public if police ask for identifying information without link to specific crime
- On PACER subcommittees: Know Your Rights, Training and Community Survey

- Member of Mental Health Committee of the Toronto Police Services Board (committee was formed as a result of an EC recommendation adopted by the jury at the Vass Inquest)
- Member Mobile Crisis Intervention Team advisory – the only community member
- TPS External Advisory Committee on Mental Health - submitted report and recommendations
- EC ED expert witness at Carby Inquest for African Canadian Legal Clinic (representing family). For first time was able to introduce possible influence of race as a factor, in addition to mental health issues, by linking to police training
- Preparing for application for standing at Loku Inquest (black man with mental health issues shot by police in CMHA housing)
- Attended Tulloch consultation on police oversight, sent submission
- Assisting TPS in development of mental health strategy
- TPS initiated EC inquest rec, and gave officer an award based on deescalating a person in crisis
- Member of Ontario Independent Police Review Director’s Advisory Committee on Mental Health. Acknowledged in *Police Interactions with People in Crisis and Use of Force OIRPD Systemic Review Interim Report*

## AWARD

LAMDA (Law and Mental Disorder Association) Advocacy Award for Jennifer Chambers

*“Outstanding fearless advocacy on behalf of clients with mental health issues in Legal Forums*

## EDUCATION

*including at Inquests and in the Supreme Court of Canada*

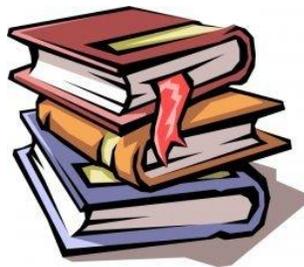
### At CAMH

- Understanding Lived Experience course content review and development. Taught course three times with Ishwar Persaud of CAMH Health Equity
- Reviewed and revised CAMH online courses on Addictions. Awaiting response to EC rewrite of CAMH online curriculum Intro to MH 101
- Bill of Rights Education LGUC
- With CAMH developed pamphlets for clients with information related to restraints and dealing with stress at CAMH

- Federal government first responders – draft RFP (not implemented – national scope)
- Educational EC Newsletter articles
- Told clients on General Psychiatry Unit and forensic units 3-1, 3-3, 3-5 about Safe Wards
- Students – Lived Realities and Advocacy
- CAMH business office – Understanding Lived Experience condensed
- Mutual education EC – Access CAMH. EC advocacy resolved lack of services for deaf clients (Charter case requiring all hospitals to ensure this access)
- Drafting public education materials on fentanyl for CAMH clients

### **SUPERVISION – VOLUNTEERS AND STUDENT PLACEMENTS**

- Supervision Student Placement Students
- Supervising Peer Researcher on Safewards Project
- Ongoing Supervision of EC Volunteers
- Management and Co-ordination of research advisees to research projects



### **Outside CAMH**

- Presentation: *“Working In Alliance With Psychiatrists, Psychologists And Other Heroes”* Discussants Brigit Mcwade And Lucy Costa, Mad Pride Week, July 2016
- Keynote: Lucy Costa: *“Madness and the Politics of Violence”* Lancaster Mad Studies Conference September 2016
- *Mental Health Training* for Legal Aid Ontario Lawyers and Advocates  
Understanding Disability for Advocates”
- Key Note *“Tensions in Peer Work”* The Ontario Act Association Niagara Falls, Ontario Conference. October 2016

- Speaker Legal Aid Ontario conference on Social Justice and the Law “*No Mental Health Without Human Rights*” – keynote panelist with Roslyn Shields
- Attended *Sound Minds II*, a daylong conference on black youth and mental health presented by Black Health Alliance
- Speaker to LAMDA Law and Mental Disorder Association about client driven advocacy
- STAR Learning Centre Advisory Committee
- Speaker at Women’s College Hospital’s conference: Trauma Talk. *Advocating for Trauma Care*. June 2016
- Train the trainer launch: Corrections Ontario mental health education
- *Looking for Advocates for Advocacy* Toronto Mad Pride Zine
- *Mental Health Law and Your Rights*, members Woodgreen Community Centre

### **Education Toronto Police Service:**

- Reviewed Toronto Police College course materials, viewed case scenarios, reviewed power point and scenario based training exercises used to educate TPS officers on unbiased policing and interacting with people in crisis or/and with mental health issues
- Attend TPS College training scenarios to assist in debriefing TPS students
- Teaching myth busting, de-escalation and trauma informed interacting with Emotionally Disturbed Persons to Toronto Police Service Mobile Crisis Intervention Team (MCIT) and backup team members
- As part of External Advisory Committee on Mental Health and Evaluation reviewed training (and hiring, psychological services and professional standards)
- Know Your Rights public education campaign developed by subcommittee PACER

### **Universities and Colleges**

- Curriculum Development: Six week Classes Pilot with Dept. of Psychiatry University of Toronto PGY1 Residents
- Lecture University of Toronto graduate students Health Policy: *Community Based Research*
- York University nursing students 6 classes per term for mental health nursing component: Myths and Realities about mental health, addiction, the systems that treat, and the people who are people first

## RESEARCH/SURVEYS

- Research Report Back “YOU MATTER! YOUR BODY MATTERS! Sex, Love, Relationships, Bodies & Access to Services A workshop for women (includes trans, cis-gender, two spirit)
- Member of CAMH Community Advisory Committee on Research
- Co-Investigators Advisory on research project on Collaborative Care (St. Michael’s Hospital)
- Preliminary stages of research partnership with CAMH First Episode Psychosis
- Partnering on research proposal with Brazilian researcher on LGBTQ Mental Health Care in Brazil and Canada. Community Based Research (as yet not funded)
- Women’s College Hospital: Video and Research – Women with Mental Health Issues Experience of Accessing Sexual Health Services
- Key Practices for Community Engagement in Research on Mental Health or Substance Use [www.keypractices.ca](http://www.keypractices.ca) Lori Ross, Joyce Brown, Jennifer Chambers, Michele Heath, Sheryl Lindsay, Brenda Roche, and Jijian Voronka
- Community survey/research re attitude toward police of marginalised community (black male youth in particular) subcommittee PACER

## PUBLICATIONS

- “Where is the client/patient voice in interprofessional healthcare team assessments? Findings from a one-day forum.” Sophie Soklaridis, Donna Romano, Wai Lun Alan Fung, Maria Athina (Tina) Martimianakis, Joan Sargeant, Jennifer Chambers, David Wiljer & Ivan Silver, [Journal of Interprofessional Care](#) Vol. 31, Iss.1, 2017
- “Barriers and facilitators to primary care for people with mental health and/or substance use issues: a qualitative study” Ross Lori, Vigod Simone, Wishart Jessica, Waese Myera, Spence Jason, Oliver Jason, Chambers Jennifer, Anderson Scott, Shields Roslyn, *Journal: BMC Family Practice*
- CAMH publication Co-authored by Jennifer Chambers: Guidelines for Communities on How to Participate in Community Based Research
- “Assisted Death – Our Last Best Judgement” In Ethics in Mental Health Substance Use, Co-Authorship Lucy Costa, Edited by David B. Cooper
- Consults, Feedback and The Future of Inclusion in System Planning
- The Access Point Consumer Reference Group Education Project and Report
- Report Launch and Client Discussion: November 2016.

## ORGANIZATIONAL

- Empowermentcouncil.ca website – maintenance and updating
- Ongoing maintenance of social media (Facebook, Twitter) communications
- Maintaining work plan as per funding agreement
- Board worked with consultant on HR
- Performance Evaluation
- Board Meetings every two weeks, Annual Board Retreat, AGM
- As CAMH consolidates, changed addiction and mental health client nominating meetings to 1 mental health and 1 addiction, from 4 site based
- Financial reports, EC Annual Audit submitted to CAMH, EC Board and members
- Use conflict of interest form and ascertain conflict at each meeting
- EC Executive meeting with CAMH about EC staff salaries lacking parity with CAMH



### END NOTES

- 1 Knutilla, Erin, 2007, Maximizing Patient Voices, Final Report for the Canadian Cancer Action Network, p.18
- 2 Coney, Sandra, & the New Zealand Guidelines Group. 2004, Effective Consumer Voice and Participation for New Zealand, A Systematic Review of the Evidence. p. 19
3. Danielle Landry (2017): Survivor research in Canada: ‘talking’ recovery, resisting psychiatry, and reclaiming madness, Disability & Society, DOI: 10.1080/09687599.2017.1322499 To link to this article: p. 9 <http://dx.doi.org/10.1080/09687599.2017.1322499>
4. Geller, et al. (1998) A national survey of consumer empowerment at the state level. Psychiatric Services 49: 498-503

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