

EMPOWERMENT REPORT

(The Newsletter of the Empowerment Council)

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Centering Madness: Building Competencies for Communities By Lucy Costa

'Patient engagement' and 'co-production' are becoming familiar terms in mental health care. While the shift from engagement to coproduction holds the promise of improving care by involving mental health patients in decision making that impacts service delivery. evidence shows the lack of a level playing field means there aren't always leadership opportunities for service users that go beyond sharing personal stories or choosing paint colours for new spaces. The work of inclusion and engagement isn't easy; it's usually uncomfortable and requires service providers to let go of power and control and remain open to alternative viewpoints. Allowing room for different views and frameworks is how you build trust and foster meaningful change.

This July, the **Empowerment Council** – in partnership with Ryerson's School of Disability Studies – took a positive step towards meaningful change, designing and delivering a six-session, competency-based curriculum for Postgraduate Year One (PGY1) students enrolled in the University of Toronto's Department of Psychiatry. The pilot project, led by myself and Lauren Munro, a community psychology researcher who has worked with the Empowerment Council on numerous projects, aimed to introduce eight medical students to the voices and experiences of service users; to teach them that the people they will be working with come from an array of backgrounds that require an understanding.

Drawing on our own experiences in the mental health system, and years of combined professional know-how (having engaged with many other service users), we delivered Centering Madness: Building Competencies for Communities.

The introductory sessions offered a range of assignments aiming to advance students' skill and understanding about the voice and experiences of service users. These classes privileged, protected, and preserved mental health service user knowledge, and incorporated discussions about the importance of understanding intersectionality, First Nations knowledge, critical race, feminist, disability and queer theory. The classes encompassed evaluations from the psychiatric residents, but more importantly, the teachers were able to evaluate the students on the basis of attendance. participation and synthesis of course material into a final presentation. This was unique and pushed the students to learn more and move out of their comfort zones.

"After the class sessions we've had thus far, I can recognize paradigms and be more culturally aware when seeing patients; have a more holistic approach to patients," said one student in their course evaluation. "I feel more open-minded and can identify and challenge assumptions, focusing on the individual needs of service users while providing care," said another.

It's been rewarding to see the patient voice recognized in an academic setting, and to have been part of this first-of-its-kind course presented by the Empowerment Council. I look forward to bringing the patient voice back to a full class of U of T residents again in summer 2018!

We are indebted to the trust of U of T Graduate Director **Dr. Mark Fefergrad** who allowed room for creativity, pedagogical exploration and trust-building throughout this process. And thank you to all of the other advisory members who informed the

conversation and understood this key point: to truly involve patients in the process of improving care, they must have access to resources and the opportunity to take on leadership opportunities themselves for their voices to be heard.

As a correlate to this project and to further discussions about power sharing and collaborative engagement within education and the psychiatric profession, the Empowerment Council produced a report entitled Engagement. It provides a short overview of some of our work, and offers a guide to assist service users and providers who are open and interested in making a commitment to eradicating systemic exclusion.

More than Paint Colours
Dialogue about Power and Process in Patient Engagement

CAMH "Phase 1D Redevelopment: Forensic Service User Advisory Report by Stef Mendolia

The purpose of the "Phase 1D Redevelopment: Forensic Service User Advisory" committee was coordinating a feedback mechanism for forensic mental health inpatient and outpatient clients to CAMH's Redevelopment Project planning team. The redevelopment of CAMH's forensic mental health system, titled Phase 1D, is scheduled to commence in **2025**, as a part of CAMH Redevelopment Project's strategic revisioning. (At this moment in time the Redevelopment is in the initial stages of Phase 1C, which is under construction at the Queen Street Site.)

The Empowerment Council's role at CAMH



with the Phase 1D, Forensic Mental Health System, & Redevelopment

Planning Project was to increase service user engagement and broader accountability to Empowerment Council membership and service user stakeholder groups.

The Forensic Service User Advisory developed a "Terms of Reference" which are agreed upon guidelines on how to work together effectively as a team, stating we will:

- 1) Represent the voice of forensic clients at the Centre for Addiction and Mental Health (CAMH) in Phase 1D Redevelopment work.
- 2) Support the CAMH Bill of Client Rights.

- 3) Speak out against prejudice, discrimination and all other human rights issues that clients experience.
- Talk about clients from a holistic perspective that offers insight into their situation, not just their medical and/or criminal history.
- 5) Strategize as a team and use consensus when needed.
- 6) Be open-minded to participants' contributions and communicate in a respectful manner.
- 7) Keep all participants' personal information confidential.

The main themes brought forward from the Forensic Service User Advisory include:

Employment, Education, Childcare, Outpatient and Inpatient care, Recreation, Security, Privacy and Conflict Issues, Advocacy and Self-Help, among others.

Some examples of what the Forensic Service User Group have said:

- "Back in the 70s everyone had a phone, now our phones are taken away for punishment."
- "Mentorship programs can be offered from outpatients to inpatients, we need a Peer Mentorship program that connects clients to support each other."
- "Comparatively from early 80s until now, programming has definitely improved – gains have been made."

- "Pro-Social" behaviour needs to be documented for our Ontario Review Board hearings."
- "Outpatients don't get to learn about what programming is offered unless they come back into the hospital. Not all outpatients have the luxury of access to a computer, which is why having a hardcopy of a calendar for programming would be ideal."
- "We should have more flexibility to sleep and rest when we would like."

Forensic Service Users Want:

- Different kinds of rooms in their space, not just a bedroom and common area.
- Cable TV in every room.
- More access to outdoor space.
- A water filter on every floor (access to fresh cold water at any time, like in the mall).
- No Seclusion Room, but that is unlikely, instead - Less use of seclusion, ultimatums, and coercion!

Phase 1D Redevelopment Visioning Day Workshop, January 15th 2018

A speech by Stephen T. of the Empowerment Council's Forensic Service User Advisory

We feel that a new design of the units would allow for better communication and therapy with staff to promote client-staff relations and help limit any violations in the CAMH Bill of Client Rights. Hopefully, the new design of the building could take into consideration some of the following:

- Provide a futuristic design to designate and rethink the trust factor of shared space between staff and clients.
- More of an advanced concept of space for clients and staff to collaborative work through goals. For example, separate private spaces for different activities, like for mental status questioning to be done. Provide a private space for clients to have groups on the unit and share feelings with each other, struggles as well. It's hard to help each other when there is not a lot of privacy in the lounge. (meeting areas).
- Allow for access to amenities for therapeutic value e.g. Nurses room, art supplies, basically keep clients active, and busy with resources on the unit, with the goal to help get off of the unit i.e. Gain Privileges.
 - Technology: Ipods, Ipads, food banks, better employment services, child care support
 - More education opportunities

- More bursaries
- · Better, more nutritious food
- More of a budget with recreation on and off units
 - More gym time (it's not appropriate for staff to have more access to gym on site than clients)
- More of a vibrant look to the building and floor (it must help improve the mood of clients)
- Focus on promoting physical health while on the floor and awareness of side effects from meds
- Interaction of the community with the floor plan and making of the building to stimulate clients to feel more at home
- More of a temporary stay at CAMH
- Businesses on and close to the property, hopefully that the clients can work at similar to Out of This World Café
- Cards given to clients to allow access to facilities to promote earnings and privileges – no tracking device as that could make clients feel violated
- Outdoor basketball courts and other physical sports facilities
- A playground staff that could supervise for clients with children

The EC hopes that the feedback of the Phase 1D Redevelopment Forensic Service User Advisory will be prioritized in the planning stages of the Phase 1D Redevelopment.

Health Quality Ontario (HQO) is looking for feedback from patients who have been admitted to hospital in the last three years. They realize that the journey home after hospital admission can be tough. A poor transition back home has been known to increase the risk of complications or

readmission. HQO would like you to share your experiences with them by completing an online survey before March 15, 2018: http://bit.ly/2F3COe0 Your input will inform health care quality Initiatives across Ontario about how to better support patients in their journey home after a hospital stay. For more information, visit http://www.hqontario.ca/Transitions.



EMPOWERMENT COUNCIL GENERAL MEMBERSHIP FORM

Contact Information: (Please Print Clearly)

Name _____ Address _____

City ____ Postal code _____

Telephone Email address

I have used mental health and/or addiction services (check those that apply):

College Street site Queen Street Other: Mental Health

Russell Street site White Squirrel Way Other Addiction

I support the purpose of the Empowerment Council: Signature

Send to: Empowerment Council, 33 Russell Street, Room 2008, Toronto, ON M5S 2S1