

EMPOWERMENT REPORT

(The Newsletter of the Empowerment Council)

Volume 4, No. 2 Winter 2012

A History (and Prehistory) of the Empowerment Council

By Jennifer Chambers

Canada who had personal experience of the psychiatric system gathered in Montreal. The conference was fittingly titled "My Turn". A smattering of allies and officials were also in attendance and organizers from around the world came to speak of how and why they were creating changes or alternatives to their country's mental health system. The troubles and the needs of people who had been in the psychiatric system in other countries rang as true in Canada as they did elsewhere. Hans Wiegant of Holland spoke of their Patient Councils, which were a voice for people in psychiatric facilities funded by the hospitals at their government's direction.

Following the conference, people from Ontario kept the momentum alive by forming the Ontario Psychiatric Survivors Alliance. OPSA had already begun organizing at Queen Street Mental Health Centre when the Ministry decided to fund two pilot patient council projects at Queen Street and Kingston. The creation of the Councils involved dealing with a number of competing interests. The peer organizers were challenged by their community members on where their loyalties would lie – would they honestly represent the concerns of their peers or would they sell out to please their funders? Could they reconcile numerous points of view? On occasion, the hospital challenged how

representative the peer advocacy organizations were - not surprising when it was common for people who were or had been inpatients to say something quite different when service providers were in the room, than when they were not. This happens in all anti oppression work, which is why one of the first things groups do is meet on their own.

Ultimately, it was agreed that in order to have an

authentic voice, the Councils would be formed by bringing together psychiatric patients/ex-patients/ survivors at each institution to form a membership that would elect a Board, who would hire their own staff. Everyone involved with the Councils would be people who had personal experience of the psychiatric system. The MOH would direct the hospitals to allocate a portion of their budget to fund the Councils. On this basis the Councils were born, at Kingston and Queen Street, in 1992.

A choice was made in favour of a Council model that supported an independent client voice. Current and former users of Queen Street voted to have their own staff as the only way to protect their rights and get real change in how services were delivered. The

alternative, being an advisory committee with hospital staff was rejected as having the same old conflict of interest suppressing real client concerns. The Ministry and hospital agreed. The Queen Street Patients Council opted to become a non-profit corporation that was responsible for its policy to its members, not its funders. Negotiations between hospital administration and its peer

advocacy organization were not without its challenges, but important joint accomplishments were made, such as inpatients having the right to lock their doors at night so that people, other than staff, could not enter without their permission. Less successful was an advocacy issue championed by the Council every year in its annual list to the hospital: the need to end the routine over medicating of inpatients. The QSPC presented research articles and the statement of the head of pharmacy in support of their position, but the response never wavered. Years later CAMH announced that PET scan technology revealed there was widespread use of excessively high amounts of medication amongst its patients. The EC noted that

clients had been saying this for some time, without the exorbitant research costs!

Neither the problems nor the solutions common to people within Queen Street stopped at the doors of the institution. As a means of doing the greatest good for the greatest number of its members, the QSPC became the first psychiatric patient/survivor group in Canada to be intervenors in a Charter case before the Supreme Court of Canada. The QSPC also became the first psychiatric consumer and survivor group to have standing at an inquest in Ontario.

In the late nineties Queen St was merged with one other mental health centre and two addiction facilities, thus creating CAMH - the Centre for Addiction and Mental Health.

The Empowerment Council History

CAMH decided that a Council was needed to represent clients at all four of its sites. The Empowerment Project was guided by a large committee of clients and families, supported by CAMH managers and consultants with academic, political and personal experience of the mental health and addiction systems. An Empowerment Facilitator was hired to create two Centre wide Councils: one for clients and one for family members. Clients named their group the Empowerment Council.

The QSPC and the EC's work overlapped for a while, so both organizations were involved in delivering weekly classes at the Toronto Police College on interacting with Emotionally Disturbed Persons, and giving talks around the province on rights and research. They were both involved in the planning and the report writing of "An Alternative to the use of Lethal Force by Police", a unique conference combining the efforts of the Urban Alliance on Race Relations, the QSPC, then the EC, and the Toronto Police Service.

The EC spent much of its first 3 ½ years negotiating between CAMH management and the clients throughout CAMH, in order to create a truly meaningful CAMH Bill of Client Rights and produced an accompanying educational DVD. To the credit of CAMH and the Council, what emerged was the strongest and clearest human rights based

hospital bill of rights in the country.

The EC has been busy trying to make the world a better place for people with mental health and addiction issues. EC has effected many changes at CAMH in policy and practice, from food to restraint use. The EC has addressed numerous Parliamentary and Senate subcommittees, and was credited with spurring the change to the Criminal Code of Canada allowing for the possibility of release of "Unfit"

accused. The EC has had standing at three inquests, and has been referred to by the Deputy Coroner of Ontario as "a good inquest citizen". As a result of one inquest, the EC was able to influence the use of restraints in psychiatric facilities throughout the province. CAMH and the EC in particular partnered to create the

conditions at CAMH to reduce the use of restraints throughout the Centre, and develop good crisis plans. Another inquest gave the EC the opportunity to make an agreement with the Toronto Police Services Board that there would be a standing committee on mental health that would use open and transparent processes. The EC is currently representing its community's concerns by asking the court to rule on whether the use of Community Treatment Orders are justified according to the Canadian Charter of Rights and Freedoms. The EC has intervened in two successful cases before the Supreme Court on behalf of people with addiction and disability. Currently it has partnered with many other organizations to oppose the federal Omnibus Crime Bill with its mandatory jail time for minor drug offences.

The EC is tiny but mighty. The organization consists of two fulltime and two part time staff, steered by a Board of clients elected from all four sites of CAMH. Lucy Costa and Tucker Gordon are the EC Advocates in Mental Health and Addiction and they are dedicated and brilliant in the work they do. Beth Jacob manages all the nuts and bolts of the organization so the EC can function, for which we are all profoundly grateful. The EC Board members bravely and with great passion debate and decide on policy directions, well led by current Chairs Susan Gapka and Beamer Smith. It is my great privilege to work with and for these people and the larger community of people who have given us the reasons and the motivation to change the world.

The Truth, the Whole Truth and Nothing but the Truth By Lucy Costa

he anniversary of the Empowerment Council has me reflecting on advocacy and its relationship to truth. Advocacy is motivated by a desire to uncover and tell the truth, usually about an injustice committed. Finding avenues to reveal the truth from clients' perspective has always been challenging because our society is organized around "quantitative" (measurable, calculable) results and not as much on opportunities that favour quality and meaningful encounters to resolve issues. Common sense has been replaced by a risk adverse society. While the 1990s into 2000 have allowed for some opportunities to speak, litigate and push for change, we still have a way to go. In fact, with the current economic climate that argues for more fiscal constraint and cuts in budgets, protecting the opportunities for "truth telling" for individuals who don't usually have their voice heard is as vital as ever.

Over the years the EC has held focus groups on a number of topics and issues in order to foster conversation or information sharing. Some of these have included: the CAMH Bill of Client Rights, ODSP, Psychiatric Survivor/Consumer History, Women's experiences, LGBTIQ's experiences, the forensic system, Community Treatment Orders, racism, Policies (such as the smoking policy), the UN Convention on Rights of Persons' with disabilities, Privacy, Court Diversion, Tenant rights, the Mental Health Act, Power of Attorney forms and many more. We have also written numerous letters to address discriminatory ads by organizations and unions whose approach was less than sensitive.

In each of these focus groups, clients, psychiatric survivors/consumers required time to express



some injustice related to the theme or topic of discussion. This need to share the story, the "truth" isn't always easy but people expel hard truths because they seek to be free from oppressive circumstances such as poverty, discrimination, exclusion and violence. These "facts" are the ones that are invisible amidst the repertoire of bureaucracies in existence to address such violations. Certain focus groups elicit larger crowds than others but always someone shows up in order to be heard. Individuals do not venture out to

simply share an opinion; the need to have someone on the other side of the conversation listen and "get it" is paramount. Our job at the E.C. is to ensure we listen carefully, and subsequently find a way to translate these stories into action and that we do so by telling, not stretching or embellishing, the truth. People depend on our integrity and honesty. Over the years we have done our best to express what has been silenced. We work to bring concerns forward by carefully choosing the best means to encourage or demand, that the hospital, government, lawyers, judges, policy makers take "a position" that will address a current situation and improve a circumstance. In the worst case scenario, this happens when it is already too late – after a death, for example, via an inquest into the truth and circumstances of that death.

At times it is difficult to do advocacy work because of systemic barriers; organizations are generally so entrenched in routine practices, with assumptions that make it difficult to work towards changing attitudes or the way people work. Sometimes it can feel like you are trying to move a mountain. However, whatever the challenges, the Empowerment Council will continue to bring truth forward, respectful of people's trust and aiming for a better and more inclusive future

Timeline of Key Social and Political Policy Changes Regarding Drug Use Compiled by Tucker Gordon

Below are some key changes that have effected the society we live in and the services we can use, in relation to our current or former drug use, with a focus on the last decade.

- > 1987 Canada's Drug Strategy launched
- > 1998 Toronto Drug Court founded (first in Canada)
- ➤ 2001 Ontario government excludes addiction as grounds for receiving Ontario Disability Support (ODSP). EC opposed this when debated at committee
- ➤ 2001 Canada becomes first country to legalize marijuana for the ill
- ➤ 2003 Canada's Drug Strategy Renewed for five years; harm reduction added as a fourth pillar
- ➤ 2004 Toronto Drug Strategy is founded E.C. currently participates in working groups
- ➤ 2006 EC intervenes in case saying that the Social Benefits Tribunal must apply the Ontario Human Rights Code, protecting the right of people with addictions to get ODSP, as addiction can be a disability. The Supreme Court of Canada rules that provincial legislation must comply with its human rights code.
- > 2007 Canada's Drug Strategy renamed National Anti-Drug Strategy. Harm reduction removed as one of the four pillars
- > 2007 Bill C-26 tabled in House of Commons introducing mandatory minimums for certain drug crimes Bill died due to an election
- ➤ 2008 Toronto Drug Users Union founded
- ➤ 2009 Bill C-15 is tabled, it is the same as Bill C-26 died due to prorogation Empowerment Council filed submission against bill
- ➤ 2010 Ontario Court of Appeal rules in favour of the Social Benefits Tribunal applying the Human Rights Code such that people with addictions now qualify for ODSP EC intervenor in the case supporting access to ODSP for people with addiction issues
- ➤ 2010 Bill S-10 tabled, it is the former Bill C-26/C-15, dies due to an election Empowerment Council filed submissions against bill
- ➤ 2010 Toronto Police Services Board Mental Health Advisory Sub-Committee adds addiction representation and greater consideration of addictions issues in their work. The E.C. is one of the addiction representatives
- ➤ 2010 Vienna Declaration created by the International AIDS Society, the BC Centre for Excellence in HIV/AIDS, and the International Centre for Science in Drug Policy. This official Declaration of XVIII International AIDS Conference calls for drug policy based on science, and a focus on drug use in all its forms as a public health issue rather than a legal issue. The E.C. has endorsed it. They're still taking organization and individual endorsements online at http://www.viennadeclaration.com/
- ➤ 2011 Ontario Human Rights Commission launches consultations on Mental Health & Disability (including addictions). Consulted with CAMH clients at E.C. invitation. They are putting out more material in the near future and may have another round of consults. You can check it out and find out where to participate at http://www.ohrc.on.ca/en/issues/mental health/topofmind.
- ➤ 2011 Commission for the Review of Social Assistance in Ontario launches community consults. Had consult round with CAMH clients at E.C. invite. There will be a second round of consults later this year, and they take individual submissions. If you want to comment in the second round, their website is http://www.socialassistancereview.ca/home.
- ➤ 2011 Bill C-10 omnibus crime bill which contains Bill S-10/C-15/C-26 and lengthens the time after the end of a sentence to be eligible for a pardon, amongst other measures. The Empowerment Council is making a submission against these changes and writing letters to representatives
- ➤ 2011 Supreme Court of Canada rules Insite can remain open