EMPOWERMENT REPORT

(The Newsletter of the Empowerment Council)

Community-based Research: Partnering with Scientists

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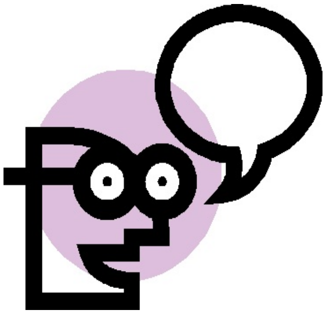
What is community-based research (CBR)? *A working group at CAMH (the Community Advisory Committee for Research), recently launched a guide for community members summarizing the issues. Excerpts from the guide, written by Jennifer Chambers and Melissa Marie Legge on behalf of the working group, are presented here:*

Research is not always seen as being friendly. The "men in white coats" have been known for doing things to us, not *with* us. Community-based research, in contrast, is about community folks being partners in *doing* the research. We can decide the questions that the research will answer. We can explain the answers. Communities can be involved in research in many different ways. Community members can:

- come up with questions to research
- decide how the research will be done (e.g. through interviews or filling out forms)
- oversee how information is collected (e.g. how people will be asked to participate)
- interpret the results (e.g. judge whether the results apply to all community members)
- decide how to communicate what was learned.

Linking science with values:

CBR connects social change and anti-oppression values with science. Historically there has been an enormous power imbalance in research. The scientist has been in control, and has explained what the research means. The people being studied have not had a real voice in what was happening, or in explaining what was found. Terrible abuses have been inflicted on communities in the name of science (such as experiments conducted on psychiatric patients for the CIA at Montreal's Allan Memorial Hospital in the 1950s and 1960s). Understandably, communities who have been harmed by research are distrustful of researchers and science in general.



CBR is a way for communities to take control of the way science gathers information, and to use it to help the community. This does not mean that community influence creates biased research. It means that the community can get at truths that people outside the community may not see or understand. The CBR approach is especially vital in communities that have lived with oppression and marginalization, such as racialized and LGBTQ communities and people with mental health challenges and/or experience with substance use. CBR creates an opportunity for mutual education between scientists and community members.

Sharing power:

There are different degrees to which power can be shared. In research in mental health, for example, "survivor research" is about people who have been on the receiving end of services having more decision-making power than the professional researchers. Power imbalances are not just about how present research is done. It is also important to examine and question the assumptions that underlie a lot of past research. For example, in research it has been assumed that there are some people who are mentally unhealthy and some who are mentally healthy, and that those in the "unhealthy" category need treatment to correct the "problem" and therefore should be studied. Often these assumptions lead to research projects that ignore the insights and experiences of people who have had the very experiences being labelled and judged.

Questions to ask:

Here are some questions, based on the principles of CBR, that communities may want to ask when they are invited to be involved in a research project.

- If I become involved in this project, what's in it for me? What's in it for my people?
- Are community members invited and able to be involved in every step of the project?
- Is the research important to the community? Could it result in meaningful changes that benefit community members?
- Are the right questions being asked?
- Does the researcher really know the community with which they wish to partner? Organizations representing community members should be involved to provide perspective beyond that of individuals, to ensure that community involvement is more than tokenistic.
- Will the community have meaningful input into the interpretation of the results before they are shared or published?
- Is there an opportunity for community members to gain skills from this experience? How will the community benefit from the research process?

These questions can be asked at the beginning of the process to help community members decide if they want to get involved with a project; partway through to check how things are going; and at the end to determine whether the partnership was productive and should be continued.

In summary, a research partnership can open doors for a community to meet its goals in ways that have previously been controlled by others. Evidence can be gathered of realities that have been dismissed as "just stories". Services that are needed can be advocated for using evidence that funders understand. Services that are *not* helpful can be evaluated using criteria that mean something to those using the service. Research can leave its dusty cupboard and be used to effect social change.

Access to Sexual Health Services for Women with Psychiatric Disabilities

Authors Lucy Costa (Empowerment Council), Andrea Daley (York University), Lori Ross (Dalla Lana School of Public Health) and Lauren Munro created a fact sheet about this topic, including contributions from the participants interviewed for their Access to Sexual Health Services for Women with Psychiatric Disabilities study, which was funded by Women's College Hospital's Women's Xchange 15K Challenge. Excerpts of their findings from the fact sheet follow:

Background: Research suggests that women with psychiatric disabilities may experience particular sexual health vulnerabilities and a need for associated sexual health services. These vulnerabilities include increased risk of sexually transmitted infections, including HIV/AIDS; lower rates of contraceptive use; unplanned and unwanted pregnancies; and higher rates of gender-based violence, including childhood sexual abuse, sexual assault and rape in adulthood, and intimate partner violence. Our project was guided by two overarching goals: (1) to develop an understanding of sexual health service access for women with psychiatric disabilities, and (2) to create evidence-informed recommendations for enhancing access to equitable, quality sexual health services for this group. In this, we have drawn on a psychiatric disabilities–informed analysis of women's experiences that attends to the ways that intersecting identities, such as racialized identities and sexual and gender minority identities, impact access to sexual health services.

What women told us about their experiences:

- Experiences of violence or trauma profoundly impacted women's need for, and their comfort in accessing, sexual health services. Women avoided hospital-based sexual health services because they felt that these services were not equipped or not willing to take account of their trauma histories. They felt marginalized, stigmatized and sometimes re-traumatized when they accessed services in the hospitals.

"Health care providers still don't know what to do when you say, 'Oh, I have a history of sexual trauma.' They're completely clued out."

- Women living with psychiatric disabilities also preferred to access sexual health services in the community because they feel safe, supported and understood.

"I always stick to my community health clinics because they're used to poor sex workers who do drugs and fuck around. And that's good for me."

- Women talked about the multiple and intersecting forms of discrimination they experienced when trying to access sexual health services, and particularly those located in hospitals. Besides having a psychiatric disability, many experienced discrimination associated with other aspects of their identities or experiences, such as LGBTQ identity, experiences of poverty or sex work, and/or racialized identities.

"The truth has to come out about the way we're being treated, especially when we go into the hospital for health care. We get all the stigma and the racism and are shuffled off to the end of the corridor and the back room."

Implications for . . .

Women's health:

Overall lack of access to trauma-informed and trauma-specific sexual health services puts women at risk as they delay or avoid preventative screening and treatment. This is a long-known phenomenon that our study findings affirm.

Institutional responsibilities:

Health care institutions need to facilitate development of the understanding, knowledge and skills required by service providers to be responsive, in non-discriminatory ways, to the complexity of women's trauma experiences, psychiatric disabilities, other marginalized social locations, and related support needs.

Governmental responsibilities:

Women we spoke with expressed preference for receiving sexual health services in community-based agencies that approach sexual health from a relational and holistic perspective and that consider impacts of trauma. Informants also expressed concern that community-based sexual health services are limited due to chronic municipal and provincial underfunding.

These findings have implications for both institutional and government responsibilities. An effective response from health care institutions might include supporting community-based women-centered services. In concrete terms, this involves advocating for proper ongoing funding for trauma-informed sexual health programs that have a history of meeting the needs of diverse women. It is crucial to incorporate a psychiatric disability analysis and recognize and build on existing community-based knowledge and practice in this process.

Collective action:

This project foregrounds the urgent need for collective action – perhaps the revitalization of the women's health movement – to advocate for resources to mobilize diversely situated women's communities, in order to determine where and how trauma-informed sexual health services should be provided. It raises questions about how to centre the voices and experiences of women with psychiatric disabilities in the creation and implementation of these services within the community, and to say very clearly to women, "You matter, your body matters. You deserve access to high quality, compassionate care".

Do you have ideas about how to improve things at CAMH? Would you like to be part of the EC's direction in the future? We are looking for clients/ex-clients to stand for election to the EC Board of Directors at the AGM this June. Interested candidates will be familiar with the EC Terms of Reference and should be prepared to speak to why they would be a good client representative and what they would add to the organization's advocacy agenda and mandate. If interested, please phone or email Lucy Costa by May 15th to discuss how you could contribute to the EC.
Lucy.costa@camh.ca, 416-535-8501, ext. 33013

Where is the Client Voice in Medical Assistance in Dying (MAiD) and Mental Health?

Mental Health Service User Considerations and Perspectives

A panel and discussion jointly presented by the Centre for Addiction and Mental Health (CAMH) and the Empowerment Council

The law now allows eligible adults suffering irremediably from terminal illnesses to request MAiD under specific circumstances. As part of its review, the Canadian Council of Academies has been asked to assess the issue of access to MAiD where mental illness is the sole underlying condition.

Our panel and discussion will:

- **Review** the current legal context
- **Hear** contrasting viewpoints from the perspective of mental health service users
- **Facilitate** discussion about how best to include mental health service users' voices in this ongoing debate.

Panelists to be announced.

All are welcome. **Priority seating for mental health service users.**

Monday June 5th, 2016

EMPOWERMENT COUNCIL GENERAL MEMBERSHIP FORM

EC Statement of Purpose: *To conduct system wide advocacy on behalf of clients.*

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**