# EMPOWERMENT REPORT

*(The Newsletter of the Empowerment Council)*

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## CLIENT EMPOWERMENT AND ENGAGEMENT IN HEALTHCARE

***By Jennifer Chambers, Empowerment Council Coordinator***

*The Empowerment Council recently produced a paper, presented to CAMH that reviewed the research literature, national and international reports on the topic of client empowerment and engagement. Below are some highlights from that review, organized by topic.*

### What IS the Client "Voice" or "Participation" in the Healthcare System?

The World Health Organisation Mental Health Legislation Checklist (2007) includes provisions to "ensure that users of mental health services are involved in mental health policy, legislation development and service planning".

### The Value of Client Engagement in Improving Mental Health Services

"The concept that the end users of health care…should be actively involved in decision-making, in both the therapeutic and economic domains, has gained wide-world acceptance" (Tomes p. 720).

"One of the most common themes was that patient voice representation provides a necessary 'reality check'" (Knutilla, p. 18).

Patient representation contributes by posing the 'So what?' questions that connect a research agenda to concrete implications (ibid).

"Recovery support should go beyond medication provision to action which enables participation in everyday life." (Kleintjes et al. 2010)

"Empowerment as a values framework recognizes that consumers have the right to gain control over their own lives, make informed decisions about how they will use mental health services and take actions on their own behalf" (Dickerson, 1998 in Brown, 2012 p. 22).

### Outcomes of Clients' Participation

"Meaningful participation can result in both subjective and objective empowerment." (Linhorst p.142) "and it can lead to tangible outcomes such as the creation of new services, improvement of existing ones, or increased access to services." (ibid)

"Patient advocates have proved most effective in reshaping the criteria for what constitutes effective treatment…" (Tomes p. 727)

### Four Reasons Clients of Mental Health Services Should Be Involved in Organizational Decision Making:

1) They have a right to participate because of the enormity of the affect these facilities can have on their lives.
2) It makes organizations more responsive to their clients needs.
3) Client participation helps reduce the power imbalance between clients and agency staff.
4) It assists clients' sense of well-being.

Katen and Prager (1986) in Linhorst p. 141

### Benefits of a Consumer Run Organization Partner:

"Empowerment is an important outcome fostered by CROs and positively related to indicators of physical and mental health" (Israel, House, Schurman, Heaney and Mero, 1989)

One randomized trial (Segal et al. 2010 in Brown) found that for consumers receiving treatment, adding involvement in a CRO led to greater personal empowerment, self-efficacy and social integration.

Mowbray and Tan (1993 in Brown) found that 77% of consumers perceived CROs more favourably than community mental health, and this is associated with organizational control, feeling accepted, and coming to the CRO out of their own free will.

Research suggests CRO involvement in system-level activities can be both effective in achieving system-level change and in enhancing the credibility, awareness and respect for consumer voices in the community (Janzen et al., 2006 in Brown 2012).

## Framework for Client Participation Structure - *Types of Voice*

Coney (2004) concludes there are 2 major types:

1) Independent consumer advocacy
2) Participation within the health sector.

The power of independent advocacy comes from organizing and taking independent media or political action in potentially oppositional ways that may be repressed in an asymmetrical relation of dependency. (Coney p.24) e.g. the movement for disability rights.

The Consumers' Health Forum in Australia has raised concern that the selection of individual health care clients to participate in health care related committees limits and controls the community's collective advocacy voice. The result is a perspective that can only address changes to individual existing services, without the ability to understand and address broader changes needed.

But there is a third alternative: A consumer organization simultaneously working 'inside' and 'outside' the system. This can allow for the legitimacy of an independent voice for consumers with the cooperation and partnership of the healthcare sector. Berry (1981) "Being an 'outside' critic has its limitations. It is better to play both sides of the street." (p. 474 in Coney p. 42)

## Process - *Representation*:

If representation is expected, people must be given the means to consult with a variety of fellow clients. A diversity of perspectives can enrich discussion, and can still form a common purpose. A vehicle for client representation must be sustainable to allow for advancement in client knowledge and understanding of the system in which they are participating. This requires resources. (Coney p. 51) Kelson (2001a) and Duff et al (1996) point to the unfairness of expecting a sole patient to represent the views of the whole patient population.

There is a need for patient representatives to be able to draw on the big picture, not just their personal experience. (Maximizing Patient Voice, Knuttila, p. 20) Being an informed patient voice is necessary for effective and meaningful patient involvement. (ibid p.22). The informed patient voice needs to have a good understanding of the decision-making body, have a broad perspective encompassing patient needs as a collective and the groups key priorities, and know the content of the committees work (ibid p.23-24).

There is evidence that consumer representatives provide more effective participation than using non-aligned consumers (Coney p. 54). They have gained an understanding of patients as a population (Duff et al. 1996). Consumer groups were able to tap into individuals who would be too frightened to personally critique services (King's Fund 2002).

### Choosing Participants:

*White (1999) and Marmor and Marone (1980) argue in favour of representatives of organized consumer groups addressing the power imbalance between the public and health professionals. They observe that administrators have a preference for handpicking or co-opting non-aligned people because they do not have the knowledge or connection to broader interests of consumers or their resources. The researchers favour selection by the groups themselves, saying this method in community action programmes in the U.S. produced the most able, universally oriented and least co-optable representatives and most independent and competent boards.*

*Accountability back to consumers is at the heart of representativeness (Coney p. 53). Consumers on committees need to report back to their group. Reps from organized consumer groups were found to be more likely to be influential and to emphasize decision-making through 'working things out' and consensus rather than conflict (Latting 1985, Godbout, 1981).*

## Barriers to Meaningful Participation

Users can feel they are not respected, that they are patronized and as if they are there as token representatives. They can feel that they are used as a legitimating exercise and that the results of participation are not used to influence services. (King's Fund 2002). Anger and frustration within the consumer sector is often based on experiences of previous involvement which has not resulted in action. (National Resource Centre for Consumer Participation in Health 1999).

Barnes and Bowl (2001) point out the conflict of interest than can occur in clients representing clients when they have what may be a legitimate fear of reprisal if they voice opinions that reflect negatively

*Representativeness* of consumers participating in health planning and policy is often raised by health professionals to invalidate consumer perspectives, by doctors in particular.  Such questions are seldom asked of health professionals. (Bastion 1994; Bowl 1996; Jewkes & Murcott, 1998; Harrison & Mart 2000).

The more experienced and knowledgeable the consumer representatives become, the more they face challenges that they no longer speak for consumers. Bastion (1998) sees this issue as one of control: people in the system raise it to justify their monopoly on choosing representatives. (Coney p. 50)

## Facilitators of Meaningful Participation

Perspectives on patient involvement can be conceptualized in terms of a continuum from consumerism (patients as customers who deserve to be satisfied) to participatory democracy (patients as citizens with rights to participate in shaping public services). Thus choosing a method to involve patients and service users is dependent on the purpose." The move across the continuum to participatory democracy involves a move from expressing simple opinions to considering broader issues - from individualism to collectivism (Gauvin p. 5).

The most effective participation occurs in the context of 'working relationships' where there is a dialogue between providers and consumers and a shift of power between them. Consumers prefer the model of partnership as the way to work. (Draper 1997, p. 77 in NZ p. 44) Anderson et al. (2002 in NZ p.44) describes the central relationship as a 'collaborating partnership'. Consumers need to be involved from the beginning of a process, not as 'add on'. (National Resource Centre for Consumer Participation in Health, 2002). *(continued on page 6)*

### Conditions For Engagement Of Clients In Meaningful Organizational Decision Making:

***Mutual trust and respect*** : clients must trust that their voices will be heard, actions they recommend will be enacted or at least considered, and that there will be no negative repercussions for critical comments. (Linhorst p. 146)

***Reciprocal concrete incentives*** to meaningfully participate together in organizational decision making i.e. People and agencies benefit from such participation. It is an acceptable way for clients to express dissatisfaction with services and have an effect on improving them, and this can result in tangible benefits for clients. (e.g. Longo et al 2002 in Linhorst p. 147 found that the members council of a long-term psychiatric hospital was responsible for improvements.) Carling (1995) encourages organizations to pay people for the time they spend trying to improve services (in Lindhorst p. 148).

***Availability of Choices*** for participants must exist in at least three areas: alternative courses of action, what issues are raised for consideration, and the choice of structures and processes through which they can participate in organizational decision-making. (L. p. 150)

***Training*** in how to participate on committees effectively is necessary for organizational decision-making (L pp144-145).

# CAMH CLIENT FORUM

## A discussion with CAMH's CEO and the EVP, Clinical Programs

Please join CAMH leaders **Dr. Catherine Zahn** and **Sarah Downey** in a conversation about CAMH's future directions:

- CAMH's Strategic Plan "Vision 20:20"
- Results of the Client Experience Survey 2012
- Changes to the programs at CAMH

The forum will be facilitated by the **Empowerment Council**.

## DATE

Tuesday, July 16
from 9:45 a.m. – 1:00 p.m.

## LOCATION

Queen Street Cafeteria

## IMPORTANT INFORMATION

*** LUNCH WILL BE PROVIDED.**

* TTC tokens will be available.

To request interpretation services, to have materials translated into another language or format, and for other accommodation needs or questions, please contact CAMH Quality, Patient Safety and Risk Management at 416 535-8501 ext. 31919. Please provide at least one week's notice if you need interpretation services.

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EMPOWERMENT COUNCIL

camh
Centre for Addiction and Mental Health
Centre de toxicomanie et de santé mentale

# CAMH & EMPOWERMENT COUNCIL HOST FORUM

***By Tucker Gordon, Systemic Advocate in Addictions***

*On July 16th, CAMH and the Empowerment Council are co-hosting a forum. It will be about the 2012 Client Experience Survey, the Strategic Plan, and the Clinical Realignment. Here's a brief summary of what these topics are***:**

## The 2012 Client Experience Survey

Results can be found at:

http://www.camh.ca/en/hospital/about_camh/performance_and_accountability/Documents/CAMH_ClientExperienceSurveySummary2012.pdf.

For the five lowest scores in the Inpatient and in the Outpatient categories, CAMH will be creating plans to improve these areas. What they will be discussing at the forum is the survey, and the next steps coming from those results.

## The Clinical Realignment

An FAQ on this can be found at: http://www.camh.ca/en/hospital/about_camh/mission_and_strategic_plan/Pages/CAMH-Clinical-Program-Realignment-FAQ.aspx. These changes come from #1 of the Strategic Plan. There's a handy graphic to show how the programs will be laid out into *Complex Mental Illness*, *Ambulatory Care and Structured Treatments* and *Underserved Populations*. They will be discussing what impact this may have on services, both now and in the future.

## The Strategic Plan: VISION 2020:tomorrow.today

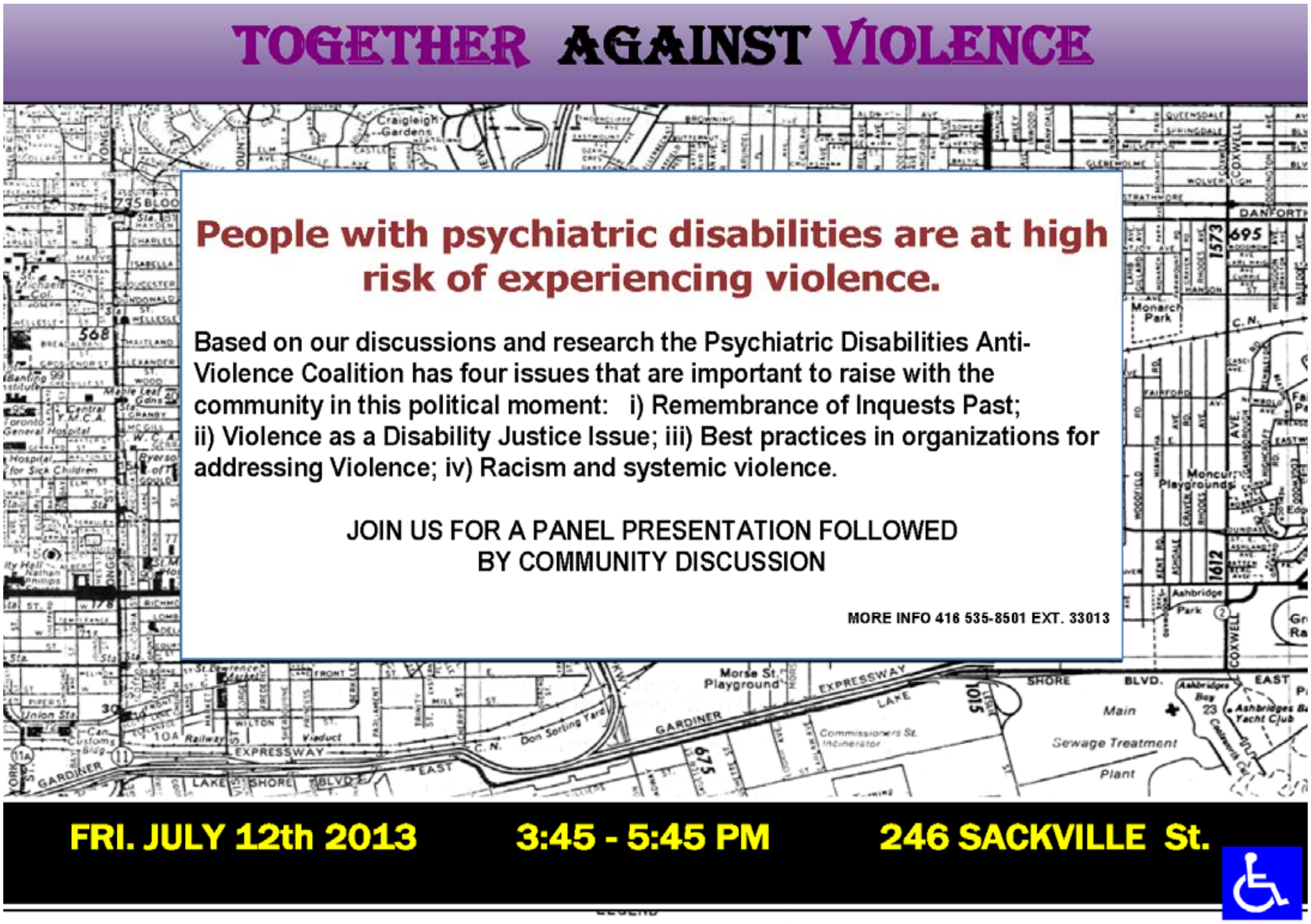
This can be found at http://www.camh.ca/en/hospital/about_camh/mission_and_strategic_plan/Pages/vision2020stratplan.aspx (*There is a stakeholder survey available on this page, near the bottom.)*

CAMH's six strategic directions are:

- Enhance recovery by improved access to integrated care and social support
- Earn a reputation for outstanding service, accountability and professional leadership
- Build an environment that supports recovery
- Ignite and discover innovation
- Revolutionize education and knowledge exchange
- Drive social change

CAMH will be discussing what they are planning on doing or are currently doing to achieve these aims. Some things you may want to consider before you attend are:

- What do you think of these six strategic directions being the areas of work they want to excel at and be known for?
- How do you think CAMH should provide integrated care and social support?
- What can or should CAMH do to create a place that supports recovery?
- What should they research? What needs innovation?
- What should they teach? How? How can clients share their knowledge?
- What social changes do you want then to push?
- Are they changes that the government needs to do, such as ODSP/OW levels? Changes within the medical community? Within the city of Toronto?



TOGETHER AGAINST VIOLENCE

**People with psychiatric disabilities are at high risk of experiencing violence.**

Based on our discussions and research the Psychiatric Disabilities Anti-Violence Coalition has four issues that are important to raise with the community in this political moment: i) Remembrance of Inquests Past; ii) Violence as a Disability Justice Issue; iii) Best practices in organizations for addressing Violence; iv) Racism and systemic violence.

JOIN US FOR A PANEL PRESENTATION FOLLOWED BY COMMUNITY DISCUSSION

MORE INFO 416 535-8501 EXT. 33013

FRI. JULY 12th 2013 3:45 - 5:45 PM 246 SACKVILLE St.

## Client Empowerment & Engagement in Healthcare – Meaningful Participation *(continued)*

Consumer councils should sit close to corporate decision-making bodies. (Commission for Health Improvement 2003). A dedicated budget is needed (Kelson 2001a). Infrastructure for participation is needed, including office space, equipment, project officers…applies to health institution and consumer organizations. (Consumer Focus Collaborative, 2003)

The role of client run organizations in partnerships with health care facilities and policy makers: “Cooptation has historically been a problem for Consumer Run Organizations (Kasinnsly, 1987 in Brown). Organizational control by consumers is required so that members can find roles in which they can purse their ambitions and control their surroundings. The disempowered and subservient roles that result from cooptation resemble the same roles traditionally found by clients in the mental health system...thus, developing strategies to establish accountability without compromising the independence of consumer initiatives is an important policy issue for mental health systems to address (Brown 2012).

## Evaluation

Case study of a consumer council and the changes it made at a psychiatric hospital. As well as “objective empowerment” (actual changes made), clients involved with the council and those who knew of the council’s accomplishments experienced subjective empowerment. This was limited by not all clients knowing of the council. Greater empowerment was hampered by a lack of choices of issues and policy alternatives. Influence was enhanced when the feedback of the council was incorporated into the hospital’s decision-making structures: issues could be brought by their liaison to the executive committee, and the council became part of the review of hospital policies. A council newsletter also helped raised the profile of council actions on clients’ behalf. (L pp 158-161)

## **Mad Pride 20th Anniversary** *By Lucy Costa, Systemic Advocate in Mental Health*

The first Toronto Pride event for mad people was held in the fall of 1993. It was called Psychiatric Survivor Pride Day. The name changed to Mad Pride in 2002 and events are now held in the summer to correspond with Bastille Day (during the French Revolution, citizens stormed the Bastille to liberate prisoners and mad people) and International Mad Pride Day on July 14, which is celebrated around the world. For more information see:

Finkler, L. (2009). Mad Pride: A movement for social change. Consumer/Survivor Information Bulletin, 398, pp. 2-3.
Reaume, G. (2008). A history of Psychiatric Survivor Pride Day during the 1990s. Consumer/Survivor Information Bulletin, 374, pp. 2-3.
Costa, L. (2008). Mad Pride in our Mad Culture: Mad Pride…say what?. Consumer/Survivor Information Bulletin, 374, p. 4.

**The Empowerment Council Presents:**

# The Mad Hatter Tea Party

## LUNACY, LAWS & LAWYERS:

**An Update on Key Topics in Mental Health**

**Guest panelists:**

**ANITA SZIGETI**
Mental Health Lawyer &
Former Chair of the Mental
Health Legal Committee

**LORNE SOSSIN**
Professor & Dean of
Osgoode Hall Law
School at York University

**LANA FRADO**
Executive Director
Sound Times
Support Services

**Wednesday, July 10th 2013**
**3:00 - 5:00 PM**
**1001 Queen Street - Cafeteria**

**This year:**
**$50.00 Prize for the**
**Best Mad Pride Hat!**

**For more information call:**
**416-535-8501, Ext 33013**

# Client Empowerment and Engagement in Healthcare - References

Brown, Louis 2012, Consumer-Run Mental Health, Springer Science and Business Media, New York

Coney, Sandra, & the New Zealand Guidelines Group. 2004, Effective Consumer Voice and Participation for New Zealand, A Systematic Review of the Evidence.

Consumer Focus Collaborative, 2001. The evidence supporting consumer participation in health.

Crawford MJ, Rutter D, Manley C, Weaver T, Bhui K, Fulop N, Tyrer P, 2002, Systematic review of involving patients in the planning and development of health care. Abstract in BMJ, Nov 30;325(7375):1263.

Duff, Lesley et al. 1996. Clinical guidelines: involving patients and users of services. Journal of clinical Effectiveness. 1(3): 104-112

Gagliardi, A. et al., 2008, Barriers to patient involvement in health service planning and evaluation: An exploratory study. Patient Education and Counselling, 70 (2): 234-241

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Hopkins, B., Law, S., Brown, B. 2011 St. Mary's Patient Engagement Project, Health Council of Canada Symposium, October 25, 2011

Kleintjes et al. 2010. Mental health care user participation in mental health policy development and implementation in South Africa. International Review of Psychiatry, Dec, 2010;22(6): 568-577

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*Mental Health: Report of the Surgeon General* (1999) from the U.S. Dept of Health and Human Services , Washington U.S. Gov. Printing Office

Roth, D. & Crane-Ross, D. (LLC 2002). Impact of services, met needs and service empowerment on consumer outcomes. *Mental Health Services Research, 4*(1), 43–56.

Emma L Simpson, Allan O House, Involving users in the delivery and evaluation of mental health services: systematic review, BMJ. 2002 November 30; 325(7375): 1265.

Tomes, Nancy, The Patient as a Policy Factor: A Historical Case Study of the Consumer/Survivor Movement in Mental Health, Regulation and Policy. May/June 2006, p.p. 720 – 729

## 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*** _____
***Russell Street site*** _____
***Queen Street site*** _____
***White Squirrel Way site*** _____
***Other: Mental Health*** _____
***Other: Addiction*** _____

**I support the purpose of the Empowerment Council**:

Signature ____________________________________

Send to: **Empowerment Council, 33 Russell Street, Room 2008, and Toronto, ON M5S 2S1**
Or fill out a membership form online at our website: *www.empowermentcouncil.ca*