MENTAL HEALTH COMMISSION OF CANADA
Stakeholder Consultation Session
October 10, 2007

EMPOWERMENT COUNCIL
SUBMISSION

The Empowerment Council (EC) is an organization that is run entirely by and for people who have received mental health and/or addictions services. EC is a voice for the thousands of people across Ontario in the catchment area of the Centre for Addiction and Mental Health (CAMH), who are addiction clients or psychiatric consumer/survivors. EC and CAMH have a Memorandum of Understanding which creates an organization that is fiscally accountable to CAMH, but accountable for policy and positions only to its membership of psychiatric consumer/survivors and addiction clients.

Jennifer Chambers
Empowerment Council Coordinator

250 College St. Room 1262
Toronto, ON M5T 1R8
(416) 535-8501 ext.4022
jennifer_chambers@camh.net

1. WHAT WOULD YOU LIKE TO SEE THE COMMISSION ACCOMPLISH OVER THE NEXT THREE YEARS?

DEVELOP ACCOUNTABILITY TO THE PEOPLE THE MENTAL HEALTH SYSTEM IS INTENDED TO SERVE

The Mental Health Commission has the opportunity to redress the discriminatory practice of exclusion or token involvement of the very people most central to any discussion of mental health and the system devised to enhance it. It was acknowledged by the Senate Committee report "Out of the Shadows at Last" [i] that consumers of mental health services must have our collective voice heard at the policy table. The Commission is to be congratulated for making a start by having two members to represent this community on the Board. However we must observe – for any other population of people would it be acceptable to have less than half the Board made up of the very people whose lives are at stake? Would a committee on women's issues consist of 10 to 15 % women? Consumers and survivors also note with concern that Advisory Committee Chairs and memberships seem to have little to no inclusion of the people most affected. Is it the perception of people making the choices that consumers and survivors' contributions will be of less value than that of other participants, that our ability to contribute is limited and therefore so must be our participation? We draw to the Commission's attention the fact that consumers and survivors provide services and run organizations, engage in legislative analysis, participate in judicial proceedings, conduct and analyze research. We should not be treated as token members. The lack of Commission sponsorship of an Advisory group for psychiatric consumers and survivors and people with addictions while offering family members such a resource is so shocking that we initially assumed it was an error of reporting. Basic to consciousness raising and the ability to organize and present a coherent voice on issues is the opportunity for members of marginalized groups to meet amongst themselves. Our organizations across Canada do not have the resources to make this happen, we need the Commission support.

Ontario has an unrivalled network of Consumer Survivor Initiatives, and has led the country in legal advocacy by members of the consumer and survivor community. Yet we have no presence on the Commission. (And I was recently told that although we have done legal advocacy work not replicated anywhere else in the country, we would not be included in the Advisory group on Mental Health and the Law, only one consumer would be included and apparently that person would be from outside of Ontario).

The most crying need for change in the mental health system across Canada is the need for accountability of mental health services to the people they are primarily intended to serve.[ii] On a policy level this means decision making based on the self identified needs of the people themselves rather than the interests of people who provide mental health services. This is the only means by which policy will support the development of an effective mental health and addiction system. [iii]

To achieve this accountability, the following changes must be made:

Resources in the mental health system should be allocated though a process that is accountable to consumers, survivors, and people with addictions, on an individual and systemic level. On a systemic level, this means that this group must be represented on governmental bodies that allocate funds to mental health and addiction services. The Toronto Central Local Health Integration Network has made a beginning to such a process, including consumer/survivors on the Mental Health and Addiction Council that will develop accountability agreements with services, having a C/S Advisory Group, and supporting a network voice of CS Initiatives in the region. At the level of services, consumers and survivors must have a significant, independent collective voice within all mental health services. (The arrangement to date between the Empowerment Council and the Centre for Addiction and Mental Health is one such example.) On an individual level, services must respond to their clients self identified needs, as this is the most effective means of achieving the best outcome. [iv] The independent living approach in use by people with physical disabilities should be also be adopted as a model in mental

health services, where funding follows the individual so she/he is able to access what is most needed, rather than being forced into certain services according to diagnosis no matter how inappropriate or unwanted a service. (Only in the mental health system is a poor match of a service with an individual called "noncompliance" and the fault of the person being ill served.)

Accountability also means requiring the mental health system to comply with the law. Psychiatric consumer/survivors need a national legal advocacy organization to address violations of their rights both under and outside the law. Let us not pretend that mental health is equivalent to any other part of the health care system in terms of its powers to involuntarily detain and treat. The awareness of these powers affects every interaction of people within the system, and people's rights must be considered paramount for mental health services to be perceived to be about care, not force. An advocacy organization must be accountable to consumers, survivors, people with addictions and mental health advocates alone to avoid the conflicts of interest that have crippled such organizations in the past. It needs to be federally funded in order to: eliminate the conflict of interest provinces might experience in supporting a mental health advocacy organization; to minimize disparity in attention to mental health rights and the consumer and survivor voice across the provinces and territories; to avoid needless duplication of effort; and to bring some level scrutiny to Canada wide mental health legislation. Such an organization can also serve as a clearinghouse for information needed by advocates across the country. A beginning would be the creation of an Advisory Committee or other body on Advocacy.

PEOPLE'S BASIC HUMAN NEEDS MUST BE MET

Income assistance must reach rates that allow persons on disability to lead healthy lives and participate in society, and everyone needs a place to live. Simply giving people who have been in psychiatric facilities sufficient funds to live above the poverty line has been demonstrated to prevent hospitalization, and therefore to save the far greater costs.[v] Contrary to popular mythology mental disturbance is more caused by that a cause of homelessness, and no mental health services will significantly improve a person's state of mind when they have no home.[vi] Employment that is flexible and humane in its treatment of workers would avoid considerable mental and emotional distress and disability. One example is Consumer Survivor run work places[vii], but humane standards must apply to all places of work.

REAL CHOICES MUST EXIST IN THE MENTAL HEALTH SYSTEM FOR SERVICES TO BE EFFECTIVE.

This is an era of an overwhelming predominance of biological explanations of human feelings and behaviour, with pharmaceutical remedies offered for all forms of human distress. There is abundant research evidence of other services and approaches that are effective, wanted, and more economical than most of the mental health services that exist today.[viii]. What psychiatric consumers and survivors need is not MORE mental health services, but more CHOICE in mental health services. Medical model services are A choice but should not be the ONLY choice. Consumer Survivor Initiatives have been found to actually save dollars by reducing days in hospital, and are generally preferred to other services.[ix]

II HOW COULD YOUR ORGANIZATION HELP THE COMMISSION AND THE MENTAL HEALTH COMMUNITY TO ACHIEVE THESE OBJECTIVES ?

The Empowerment Council has presented to Committees of the Legislature and Senate on proposed legislation and policy, intervened in Court cases and Tribunals, had standing at inquests and with CAMH developed a Bill of Client Rights that is the best of its kind in the country. We conduct focus groups and consultations with clients of CAMH on their needs in the mental health and addiction systems. We analyze research for best practices to meet clients self identified needs. We are a systemic advocacy voice that could assist the Commission in ascertaining consumer/survivor priorities, needs and rights when rebuilding a system based on care and citizenship.

Jennifer Chambers, Empowerment Council Coordinator

Endnotes

[i] "Consumers of mental health services must be given the opportunity to participate actively in the process of collective decision-making. Their collective voice must be heard at the policy table, just as they should be allowed to make individual choices about which services and supports are right for them." p.6 Out of the Shadows at Last *Highlights and Recommendations* May 2006

[ii] *Achieving a Patient-Oriented Health Care System*

Principle Seventeen

Canada's publicly funded health care system should be patient-oriented.

In Canada currently, the health care system is organized around facilities and providers, not individual Canadians. People are expected to fit into the system and get service when and where the system can provide it.

In other countries, changes have been made to put more focus on patients. This includes introducing health charters or care guarantees to ensure that people get the care they need within a certain period of time and of acceptable quality. This also includes establishing a system in which funding follows the patient.

It is the view of the Committee that patients, at all times, must be at the centre of the health care system
from report of the Standing Senate Committee on Social Affairs, Science and Technology (2.4p)

[iii] The (U.S.) National Council on Disability observed that "policy making based on input from experts, and that excludes participation from people labeled with psychiatric disabilities themselves, results in wasteful and ineffective one-size-fits-all public policy that doesn't efficiently meet the needs of those it is intended to serve."[iii] "The National Council on Disability has also concluded that one of the reasons public policy concerning psychiatric disability is so different from that concerning other disabilities is the systematic exclusion of people with psychiatric disabilities from policy making." National Council on Disability, "From Privileges to Rights: People Labeled with Psychiatric Disabilities Speak for Themselves", January 20, 2000, p. 21

[iv] D. Roth et al, "LCO Project Description." SAD, Office of Program Evaluation and Research, Ohio Dept of Mental Health, 1998

[v] H.Lafave, et al "Partnerships for People With Serious Mental Illness Who Live Below the Poverty Line". Psychiatric Services, (1995) 46, 1071-1073.

[vi] R. Simons et al "Life on the Streets: Victimization and Psychological Distress Among the Adult Homeless". Journal of Interpersonal Violence, (1989) (4)

[vi] S. Rosenfield, "Homelessness and Rehospitalization: The Importance of Housing for the Chronic Mentally Ill." Journal of Community Psychology, Vol. 19, 1, 60-69

[vii] J. Trainor and J. Tremblay, "Consumer/Survivor Business in Ontario: Challenging the Rehabilitation Model", Canadian Journal of Community Mental Health, Vo. 11, No. 2, Fall 1992, p.p. 65 - 71

[viii] V. Lehtinen et. al. "Two-Year Follow-up of First Episode Psychosis Treated According to an Integrated Model: Is immediate neuroleptisation always needed?" European Psychiatry, 2000. 15(5): 312-320.
L. Mosher "Soteria and other alternatives to acute hospitalization: A personal and professional review." Jour. Nerv. Ment. Dis. 1999, 187: 142-149.
Matthews SM, Roper MT, Mosher LR, and Menn AZ. "A non-neuroleptic treatment for schizophrenia: Analysis of the two-year post-discharge risk of relapse". Schiz. Bull. 1979 5: 322-333.

[ix] J. Trainor, M. Shepherd et al, "Beyond the Service Paradiagm: The Impact and Implications of Consumer/Survivor Initiatives", Psychiatric Rehabilitation Journal, Fall 1997, Vol. 21 No. 2, p.p. 132-140
J. Trainor and J. Tremblay, "Consumer/Survivor Business in Ontario: Challenging the Rehabilitation Model", Canadian Journal of Community Mental Health, Vo. 11, No. 2, Fall 1992, p.p. 65 - 71