PRIORITIES FOR GOVERNMENT RESPONSIBILITY IN THE MENTAL HEALTHCARE SECTOR

SUBMISSION TO THE STANDING SENATE COMMITTEE ON SOCIAL AFFAIRS, SCIENCE AND TECHNOLOGY

BY THE EMPOWERMENT COUNCIL, SYSTEMIC ADVOCATES IN ADDICTIONS AND MENTAL HEALTH June 30, 2003

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 (a term many prefer to patients). 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.

ACCOUNTABILITY OF THE MENTAL HEALTH SYSTEM TO THE PEOPLE IT SERVES

An effective mental health system is governed by the needs of the people it exists to serve. This is not the current system, which is governed primarily by the interests of those who work in the system, and by political interests that often reflect public prejudice more than reasoned decision making.

The Empowerment Council recommends that the mental health system conform to the ideals expressed in the report of the Standing Senate Committee on Social Affairs, Science and Tecnology (2.4p):

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.

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

Resources in the mental health system should be allocated though a process that is accountable to c/s's, on an individual and systemic level. On a systemic level, this means that consumer/survivors must be represented on advisory committees to all government bodies that allocate funds to the mental health system. These people should be chosen by elections within their own community. On an individual level, the independent living approach in use by people with physical disabilities should be adopted, where funding follows the individual so she/he is able to access what is most needed, rather than being forced into certain services because they are the only ones funded to serve her/him. We must be able to "vote with our feet".

Mental health and addiction related organizations and services must be primarily accountable to people with first hand, lived experience of emotional/mental disturbance and addiction. The health care system should be organized around the people it exists to serve, not around facilities and providers. The relationship between the EC and CAMH is a start at greater accountability of a facility to the people that it serves.

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. This organization must be accountable to consumer/survivors alone to avoid the conflicts of interest that have crippled such organizations in the past. This organization needs to be federally funded in order to: eliminate the conflict of interest provinces might perceive in supporting a mental health advocacy organization; to minimize disparity in attention to mental health systems and the consumer/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. This would require a reallocation of funding currently spent elsewhere.

No legislation or public policy effecting psychiatric consumer/survivors should be drafted without significant participation or consultation with the people who will be most effected by it. "Nothing about us without us". It should not be considered acceptable to draft policy effecting a group of people without significant consultation with these people. We may be the only group in Canada enumerated under the Charter where it is not just acceptable, but routine, to ignore us when discussing our people and matters that effect us.

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, 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.¹ Contrary to popular mythology mental disturbance is more caused by than a cause of homelessness, and no mental health services will significantly improve a person's state of mind when they have no home.²

Employment that is flexible and humane in its treatment of workers will prevent, improve and even "cure" a lot of mental and emotional distress and disability. One example is consumer/survivor run work places³, but humane standards must apply to all places of work.

3. 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 solutions to all of human distress. There is abundant research evidence of services and approaches that are more effective, more wanted, and more economical than most of the mental health services that exist today, 4 yet vested interests maintain this unbalanced system. Please see our submission for more detail on facts neglected by the current system: that the majority of consumer/survivors have suffered abuse that is never addressed in the mental health system; and that psychiatric medications are helpful to some but of limited effectiveness, and can cause considerable harm. What psychiatric consumer/survivors need is not more mental health services, but more CHOICE in mental health services.

¹ H.Lafave, et al "Partnerships for People With Serious Mental Illness Who Live Below the Poverty Line". <u>Psychiatric</u> Services, (1995) 46, 1071-1073.

² R. Simons et al "Life on the Streets: Victimization and Psychological Distress Among the Adult Homeless". <u>Journal of Interpersonal Violence</u>, (1989) (4)

² S. Rosenfield, "Homelessness and Rehospitalization: The Importance of Housing for the Chronic Mentally III." Journal of Community Psychology, Vol. 19, 1, 60-69

³ 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

⁴ V. Lehtinen et. al. "Two-Year Follow-up of First Episode Psychosis Treated According to an Integrated Model: Is immediate neuroleptisation always needed?" <u>European Psychiatry</u>, 2000. 15(5): 312-320.

L. Mosher "Soteria and other alternatives to acute hospitalization: A personal and professional review." <u>Jour. Nerv. Ment. Dis.</u> 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". <u>Schiz. Bull.</u> 1979 5: 322-333.

We need some services to be funded that are not based on the medical model, and that do not deliver pharmaceutical solutions. Medical and medication based services should not be the ONLY choice. For Canadian examples of some successes using this approach, see consumer/survivor initiatives, and nonmedical servcies such as the Gerstein Crisis Centre in Toronto.

Consumer/survivor initiatives need to receive a significant portion of mental health spending throughout Canada. Research evidence indicates that c/s's prefer these initiatives over other mental health service, and that c/s initiatives actually save dollars by reducing days in hospital.⁵

People with addictions have many of the same underlying issues as people in the mental health system. Yet addiction services have often developed as more egalitarian, less medical model, and more holistic than mental health services. While some people with addictions can benefit from additional support, there is a fear that the increasing overlap of addiction and mental health services will result in losing these valued approaches, while increasing the tendency of people with addictions to be given other drugs to rely on. The Empowerment Council hopes that the mental health system might learn from the addictions system how to better respect people as the ones that must determine their own lives, yet there we are concerned that we are heading in the other direction.

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⁵ J. Trainor, M. Shepherd et al, "Beyond the Service Paradiagm: The Impact and Implications of Consumer/Survivor Initiatives", <u>Psychiatric Rehabilitation Journal</u>, Fall 1997, Vol. 21 No. 2, p.p. 132-140

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