Empowerment Council
A voice for clients at the
Centre for Addiction and Mental Health

CLARKE SITE: 250 College St, Room 1262, Toronto, ON M5T 1R8 (416) 535-8501 ext.4022 jennifer_chambers@camh.net
QUEEN STREET SITE: 1001 Queen St W, Room 160, Toronto, ON M6J 1H4 (416) 535-8501 ext. 3013 lucy_costa@camh.net

CONSULTATIONS ON MENTAL HEALTH

Standing Senate Committee
ON SOCIAL AFFAIRS, SCIENCE AND TECHNOLOGY

ADVOCACY IN MENTAL HEALTH AND ADDICTIONS

February 15, 2005

Submission by the
EMPOWERMENT COUNCIL

The Empowerment Council (EC) is a member run advocacy organization formed to act as a voice for people who have been in the mental health and addiction systems. The EC's Board, general membership and staff consist entirely of people with this personal experience. Our catchment area is Ontario, consistent with that of the Centre for Addiction and Mental Health (CAMH), where we are based.

Deputation by Jennifer Chambers

Advocacy means our people having a voice in matters that effect us, as long as the voice heard is indeed ours and no one else's. Most often, we are silenced by social exclusion, and drowned out by voices that claim to speak for us. By speaking to you in this forum we are trying once again to achieve our basic human rights and necessities of life, to persuade you that we want our self defined needs met, not needs that others may claim to be ours.

In the first series of consultations by this Standing Committee, the people most effected were almost completely excluded. "The National Council on Disability has 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**."[1] We appreciate the effort made to include a greater proportion of our community in this forum. Yet still we are a minority in discussions about our own lives and well being. This is in part a reflection of our exclusion from power in the mental health system itself.

The word advocacy is from the root "ad voce" meaning to give voice to – clearly we need better opportunities to be heard in all matters that affect us, because we have much to say. Our voice should not be confused with anyone else's. Our interests are not the same as families or service providers, although they may overlap at times - but that is for us to say.

Because it is rare indeed for psychiatric consumers or survivors, or people with addictions to have any effect on politicians, policy makers, planners or services, **we often have to turn to the courts to acquire our basic rights of citizenship**.

On behalf of organizations of psychiatric survivors and people with addictions, I have facilitated our presence in 4 court cases and 3 inquests. The 3 cases that reached the Supreme Court of Canada were all victories, which is possible because only there have we (thus far) been able to count on our rights under the Charter prevailing over social prejudice and the powerful family and professional lobby. (Not all family groups and all professionals oppose our rights, but many are predictable proponents of more coercion.) The SCC has, to our benefit, described how a forensic mental health system would operate that does not violate the Charter rights of people in the system, that least restrictive does indeed refer to whether someone is held in maximum or minimum security, that refusing one particular treatment does not mean that one is incapable of making treatment decisions.[2]

Acquiring our rights in this fashion is time consuming, piecemeal, and is counteracted by the tremendous efforts made by service providers to thwart the meaning of the SCC's rulings. We are typically opposed by hospitals, family groups, Ministries, and at times Review Boards. Our side educates lawyers, accumulates evidence, makes arguments, and we are found to be right. It is a gain and an important one, but powerful people with vested interests in the status quo diminish the impact as much as possible.

Ongoing advocacy is needed, with a coordinated national strategy. As noted by McCubbin and Cohen, "rights are not protected because they are rights, they are rights because they are protected."[3] They observe that the very term "right" is today being distorted by rights opponents by applying such terms as "right to treatment" to justify more forcing of treatment.[4]

Even the legal system systematically excludes most psychiatric consumers and survivors form real access to justice. MHLAC (with the EC in Toronto) has conducted the only survey that has ever been done asking people detained in the forensic system about their view of the system. More times than not, questionable legal advice to plead NCR resulted in their being captive in an arbitrary system for 5 or 10x longer than the maximum they would have served had they been convicted of the crime. The man whose inquest is talking place in North Bay right now hung himself after many years in the forensic system with no apparent hope of release, for an incident that might have resulted in no jail time at all.

Added to this is the unwillingness of doctors to testify in opposition to another doctor, and the unwillingness of lower courts and tribunals to consider the array of evidence available to challenge a medical opinion. **Consistent, organized, education and pressure must be brought to bear to make the judicial system a just one for most psychiatric survivors. This requires the expertise of a national mental health and addiction legal advocacy organization, controlled by psychiatric survivors and people with addictions.**

Why Our Lives Depend on Real Advocacy

Researchers at the Roeher Institute found that "Research findings on violence against persons with disabilities in institutional settings reach remarkably similar conclusions: the scale of the abuse against persons with disabilities appears to be of a substantial magnitude…Staff reporting of violence against persons with disabilities appears to generate an estimate of incidence that is lower than when respondents are persons with disabilities themselves."[5]

Other Roeher Institute researchers concluded that "Overall, there is a pattern of inconsistent response to the victimization of persons with disabilities...the luck of the draw seems to determine whether victims with disabilities will be responded to in a suitable manner...There is a prevailing sense that justice is not being served."[6]

To examine the extent of the problem of violence facing people with disabilities in general, with examples of people from the psychiatric system in particular, see the results of a review of the literature Appendix I.[7]

In addition to criminal abuse, the more consistent abuse of the rights of people in the mental health system is the constant violation of our right to certain protections under the law.

“Other examples: ‘informed consent’, …study after study, added to what we have heard from users themselves, show that few users are informed about the undesirable effects of the psychoactive medications prescribed for them. The notion of ‘least restrictive treatment’, while it had only partial recognition in earlier times, is now being used to advance coercion in the community via outpatient civil commitment orders. The ‘right to refuse treatment’ has become completely subsidiary to the issue of the users’ competence, which is often questioned more because of the <u>fact</u> of treatment refusal rather than any assessed lack of decision making capacity leading to refusal.”[8]

McCubbin and Cohen go on to observe that the criterion of “dangerousness” applied to psychologically distressed persons has come to be defined in practice as perceived need for treatment. They observe that this reflects Appelbaum’s argument that the system operates in accordance with the public and professional attitudes toward the “mentally ill”, not according to the written law. Despite danger having little to do with the application of the concept, they observe that nevertheless family lobby groups seek to broaden the concept still further.[9]

To speak from my personal experience: Being on a psychiatric ward was a traumatic event in my life. There is a peculiar view of a person on a psychiatric ward, as though all the elements of an experience that would clearly be devastating in another context are somehow suspended in their meaning for that person because they occur in a “hospital” environment. People are locked in little rooms they can’t leave, tied to a bed, injected with drugs against their will, punished often for being considered too emotional, or too loud…what would be considered normal or at worst a nuisance in most places – hardly calling for such violence.

All I can say that psychiatric wards offered me, was the sense that compared to them, the rest of the world was better. And how screwed up is this? That the places our society sets up for people to go to in their deepest distress are often scary, cruel places where whatever self hatred you came in with gets validated and increased. My outrage that this should ever be so is why I do the work I do.

A redistribution of power and real advocacy is required in the mental health system before our rights will have much meaning. See Appendix II for a description of the empowerment and advocacy mechanisms that are required in psychiatric facilities for our community members’ rights to be protected.

Since this article was written, the Empowerment Council and the Centre for Addiction and Mental Health have created a Bill of Client Rights (See Appendix III), which the Centre has recently adopted. It was developed through our extensive consultation with the clients of the Centre. Every right is based on real needs expressed by our members. To the best of our knowledge it is the most powerful Bill of its kind in Canada. It is not perfect, but if/when followed (it is just being launched at CAMH) the difference could be remarkable. It or something like it should be required at each facility. This Bill is as strong as it is because the Centre has agreed to support an independent systemic advocacy voice for clients. Every psychiatric facility in the country should have such a member run voice within it.

Note that our Bill is <u>not</u> accompanied by a section called “Responsibilities” as are many hospital Bills. It is another example of the patronizing approach to patient rights that such sections should be attached – are women’s rights written up with an attachment on women’s “responsibilities”? Such qualifiers again illustrate the conflict of interest that can result when anyone other than consumers, survivors, people with addictions, and our advocates, are our voice on our rights.

What is Real Advocacy?

The Ontario Advocacy Commission, a brief but admirable centre of Advocacy controlled by people with disabilities described advocacy: “At its most powerful, it’s a way to help people “own” their own lives.”[10] They go on to note that “Unlike most health care or social services, advocacy is directed by the vulnerable person.”[11]

Advocacy can be individual or systemic. Individual advocacy may be: self-advocacy which is ideal as the most empowered; individual instructed advocacy in which the advocate is directed by the individual to speak for her/him; or in extreme cases where a vulnerable person is incapable of instructing and their safety or life is at risk, non-instructed advocacy in order to have the appropriate person(s) remedy the danger – this does not include being a substitute decision-maker.[12]

“Systemic advocacy is about changing systems – governmental, legal, economic, social and institutional - to benefit a broad range of people who face common issues. By changing laws, rules, regulations, policies, and practices, systemic advocacy can resolve a widespread problem more efficiently than the individual approach. Systemic advocacy is about changing values and attitudes…also about changing power relations. Systemic advocacy is, of course, shaped and informed by the issues of individuals.”[13]

In Ontario today we have the Psychiatric Patient Advocate’s Office, which delivers individual advocacy at their client’s direction, and as a separate organization is not controlled by the hospitals at which they serve. Their presence in some psychiatric facilities in Ontario is a vital alternative to hospital hired “advocates”. However their independence has been under pressure in recent years. Divestment of Provincial Psychiatric Hospitals has meant that the Ministry can no longer direct hospitals to accept their services. By having to “apply for the job” their independence is weakened.

They also have no involvement of psychiatric consumers and survivors either as an advisory body or a governing Board. An advocacy organization existing solely to represent the voice and rights of consumers and survivors should be accountable to our community. To be accountable to anyone else (other than fiscally) is a conflict of interest.

Patients Councils across the province have been unpredictably affected by the same divestment process. While the Ministry of Health used to require hospitals to fund Councils that were accountable to their members, upon divestment some hospitals stripped Councils of their money, independence, and staff.

There is no Ontario wide systemic advocacy voice of psychiatric consumers and survivors or people with addictions, nor is there a national advocacy voice of our community. We need organizations to represent our voice, and we need ones that exemplify the principles of good advocacy.

"For the Commission, advocacy is founded on two key principles: independence and trust. An advocate must be independent, free from any real or perceived conflict, an advocate must be trusted to represent the interests of the vulnerable person and only the interests of the vulnerable person."[14]

RECOMMENDATIONS

A National Mental Health Legal Advocacy Organization

Accountability means requiring the mental health system to comply with the law. Psychiatric consumer and survivors and people with addictions need a national legal advocacy organization to address violations of their rights both under and outside the law. This organization must be accountable to the community it is meant to serve and us alone. Taking direction from psychiatric consumers, survivors and people with addictions avoids the conflicts of interest that are inherent in organizations that have not operated according to this principle. (The Ontario Advocacy Commission, for example, was plagued with problems as a result of a political decision to place people on its Board that were not members of the disability community served by the Commission.)

Avoidance of actual and perceived conflict of interest also requires that this organization exist for the purpose of advocacy and only advocacy. Organizations that claim to deliver advocacy while providing other services have an obvious bias in favor of the service they deliver, which tarnishes their credibility.

A federally funded national mental health legal advocacy organization is required in order to: avoid all the duplication of effort in legal advocacy across the country and support local advocates; to bring some level scrutiny to Canada wide mental health legislation and its various degrees of compliance with the *Canadian Charter of Rights and Freedoms* in each province*;* eliminate the conflict of interest of provinces funding a body that will challenge provincial mental health legislation and provincially funded health care services; to minimize disparity in attention to mental health systems by advocates across the country; and to articulate the consumer and survivor voice in mental health advocacy across the provinces and territories;. Such an organization can also serve as a clearinghouse for information needed by advocates across the country.

The advocacy organization would conduct test case litigation and policy analysis, so provincial advocates need not reinvent the case every time their government considers new legislation. It would have the ability to analyze relevant social science and medical literature. (One of our repeated requirements as intervenors in court cases has been to provide research evidence that challenges the received wisdom of the professionals who have testified – but it is not enough to have our rights across the country affected by the chance nature of our research abilities and intervention in a few cases.) Its guiding principles would be the advancement of citizenship rights, equality and self determination for all people identified under the *Charter* as having or being perceived as having “mental disability”. The Committee might care to examine the U.S. model of the Bazelon Centre for Mental Health Law as an example of such an organization.[15]

This organization might also assist with the creation of a national Bill of Patient Rights.

For the Empowerment Council’s Recommendation Priorities submitted to the Committee previously (but possibly not received) please see Appendix IV.

RESPONDING TO SELECT QUESTIONS OF REPORT #3

Personal Care Plans in which the money follows the individual could be the only incentive that will lead to the tremendous change required for mental health systems to become places of recovery and empowerment. We recommend that the approach of the Centres for Independent Living be examined, who assist people with physical disabilities with this process. Care plans <u>must</u> be based on the individual’s self identified needs, and those alone, lest they become a new instrument of coercion and have the opposite of the intended effect. For far less than the cost of an approximately $500 day in a hospital, an individual could purchase 24 hour personal support attendants (not that people would generally want or need as much.)

But personal care attendants will only be one piece of the needed change. **There must be genuine choice through real alternatives to the present system.** Alternatives have been tried, tested, researched, and verified in countless peer reviewed articles, and their absence from the scene is explicable only by understanding the overweening influence of biomedical psychiatry on mental health care funding. One successful alternative to hospitalization that was extensively researched and published was known as “Soteria House”, whose tenants fared better than the control group who were hospitalized. [16]

See our recommendations in Appendix IV regarding system **accountability** to the people on the receiving end of services and the article in Appendix I on **empowerment**.

No government of health service should approve policies affecting our community without thorough consultation with our community. We support the proposal of an advisory committee to the federal and each provincial government in order to facilitate a patient-oriented system IF this committee contains a majority of our community and our chosen advocates, the most relevant participants in creating a new and better alternative to this system.

Before drafting your final report, we propose that this Standing Committee of the Senate call an advisory panel of psychiatric consumers, survivors, and people with addictions to provide a sense of the real life impact of the recommendations that this Committee will be considering. We need this Committee of the Senate to rise above the political pandering to prejudice that prevails in legislatures. (The recent consultations Victim Impact Statements in Bill C-10 are such an example.)

As a result of not hearing from us to any significant degree, your reports, while including some worthy information, reflect the biases of the narrow group of presenters. The reports do not, for example, reflect the danger that psychiatric medications can pose. There is no indication of the considerable research evidence showing the high incidence of brain damage and increased mortality from the use of psychiatric medications[17], instead the Committee heard almost exclusively from those who seek to further advance its use.

“It is crucial to consider who has power in the formulation of mental health policy. Traditionally, consumers of mental health services have been perceived as the objects, rather than agents, of policy. A redistribution of power is necessary on the grounds of therapeutic benefit/empowerment, “but also due to the very pragmatic reason that the objectives of a reform will best be met in the long run by placing control of the shaping of the reform in the hands of those whose interests are most consistent with the reform objectives.”” [18]

ENDNOTES

[1] National Council on Disability, "From Privileges to Rights: People Labeled with Psychiatric Disabilities Speak for Themselves", January 20, 2000, p. 21 http://www.ncd.gov/newsroom/publications/privileges.html

[2] See *Winko, Pinet/Tulikorpi, Starson*

[3] McCubbin, M. and Cohen D., *The Rights of Users in the Mental Health System: the Tight Knot of Power, Law and Ethics,* paper presented to XX!Vth International Congress on Law and Mental Health, Toronto, June 1999
[4] ibid
[5] The Roeher Institute, *Violence in Institutional Facilities Against Persons with Disabilities – A Literature Review, 1999, p.3*

[6] The Roeher Institute, *Harm's Way, the Many Faces of Violence and Abuse against Persons with Disabilities*, 1995, p.119

[7] The Roeher Institute for the National Clearing House on Family Violence, *Violence and People with Disabilities: a Review of the Literature,* Family Violence Prevention Division, Health Canada, August, 1994, Prepared by Miriam Ticoll, p.p. 16 – 18

[8] McCubbin, M. and Cohen D., *ibid*, p.4 and referencing Cohen, D., and Cailloux-Cohen, S. *Guide critique des medicaments de l'amees,* Montreal,: editions de L'Homme, 1995 p.p. 3-4
[9] ibid and referencing Appelbaum, P. *Almost a Revolution: An international perspective on the law of involuntary commitment,* Journal of the American Academy of Psychiatry and the Law, 1997, 25, 135-147

[10] Ontario Advocacy Commission, *Advocacy: Now More Than Ever,* February 1996 p.4
[11] *ibid, p.5*
[12] *ibid*, p.p. 6-7
[13] *ibid*, p.7
[14] *ibid*, p. 30

[15] see: bazelon.org

[16] See: www.mosher**soteria**.com/soteri.htm

[17] Ballesteros, MD et al, *Tardive Dyskinesia Associated with Higher Mortality in Psychiatric Patients: Results of a Meta-Analysis of Seven Independent Studies,* Journal of Clinical Psychopharmacology, vol. 20, 2000, p.p. 188 – 194

[18] McCubbin M. & Cohen, D. *A Systematic and Value-Based Approach to Strategic Reform of the Mental Health System*, 7 HEALTH CARE ANALYSIS 57, 67 (1999) within article in progress by Aaron Dhir, University of Windsor - Law