ROUNDTABLE ON MENTAL HEALTH

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ON SOCIAL AFFAIRS, SCIENCE AND TECHNOLOGY

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Submission by the
EMPOWERMENT COUNCIL

The Empowerment Council (EC) is an 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.

Note: Although this discussion is about people who have been in the mental health system, the underlying issues for people with addictions are much the same. Addiction is a particular response to much the same distress. The social prejudice is a little different for each, but has a number of similarities.

EMPOWERMENT COUNCIL
Centre for Addiction and Mental Health, Clarke Site
250 College St. Room 1262, Toronto, Ont. M5T 1R8
(416) 535-8501 ext. 4022 Fax: (416) 260-4128
jennifer_chambers@camh.net

ATTITUDES AND BEHAVIOUR TOWARD PEOPLE WHO HAVE BEEN IN THE MENTAL HEALTH SYSTEM:

A NATIONAL DISGRACE

This paper will look beyond the effects of the general public's prejudice toward our community, to also consider the discrimination that allows for the exclusion of our community's voice, and the injustices and misdeeds that occur in the mental health system and in public policy as a result.

The term "stigma" is an example of the degraded standard of human rights that is applied to people who have been in the mental health system. Prejudice can be addressed by a human rights commission, for discrimination there are remedies under the law. But these same experiences, when they happen to persons with psychiatric labels, warrant a different term, for which there is no legal recourse. Why is that? It is not because people using it have ill will. Yet despite psychiatric consumers and survivors (c/s's) having raised this issue, the inequity of terminology and all its implications persists.

Mental Health System Oppression (as some of us have deemed it) is part of our culture - it is everywhere, and we learn it young. It does not take long for a young person to learn that being "weird", not being "normal" is a terrible thing, for which you will be isolated. If you seem <u>really</u> "weird" they will take you away, lock you up. Everyone in society is victim of this oppression. We all make ourselves less in order to fit in. But once you have been in the mental health system, you may not be allowed to fit back in.

… the true, unrecognized source of social bigotry, (is) that literally every woman, child and man walking the earth has a capacity for madness within them, without exception. One variable is the trigger, of which there are perhaps as many variations as there are human beings on the planet. Another is in how the phenomena is apt to manifest itself once the trigger has been pulled - again, such variables are as numerous as is humankind itself. But the basic capacity for a sudden, dramatic shift in perception, belief structure, personal goals, feelings - in fact, the very foundations of a typical life structure - is an attribute shared by all of us, without exception. It is also an attribute that evokes stark terror in most people.
Graeme Bacque

One result is a pervasive discrimination experienced by c/s's. Unlike any other group enumerated under the *Charter*, it is considered acceptable to hold consultations, make decisions, draft policy, run organizations, with little to no involvement of the community on whose behalf all of these activities ostensibly exist to serve. Would discussions about women, or people with physical disabilities, or people of colour take place with large numbers of people talking about these communities, while members of the groups themselves were almost completely excluded?

This is not raised in order to blame, but to point out that the attitudes held by most of Canadian society allows such behavior to proceed unquestioned, because the false beliefs about our community are so wide spread. Any other group in our position would proclaim that they have been treated with bigotry and contempt. Is there a reason we should feel differently? As with any group - racial minorities, people with physical disabilities, women and men - we are the experts on our lives, our experience and our needs. It is important to hear what we need from us.

What are the problematic attitudes that keep c/s's from being perceived and treated as equal to other Canadians? Some of the prejudice toward our community is so deeply ingrained in this culture that it is throughout the language, the entertainment and news media, in epithets, casual conversation and public policy. As with all stereotypes of disadvantaged groups, these attitudes and their effect on behavior are rooted primarily in ignorance - a lack of information. Even more dangerous to c/s's is when misinformation is represented as factual by mental health professionals. These are the experts to whom well meaning people and policy makers turn when they want to be well informed and make good decisions. Biases and conflicts of interest that exist in the field go unrecognised. It is akin to relying on people who work in nursing homes to teach you all about seniors - their perspective has limitations and biases.

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."[1]

"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."[2]

Myths and Stereotypes that Endanger People with a Psychiatric Label

1. The Attribution of Dangerousness

A study comparing people in the same neighborhood who had and had not been in a psychiatric facility found that people who have been in a psychiatric hospital are not more violent than other people in their community.[3] The only exception is that immediately after discharge if substance

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[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] ibid, p. 6

[3] H. Steadman et al, "Violence by people Discharged from Acute Psychiatric Inpatient Facilities and By Others in the Same Neighborhood", Archives of General Psychiatry, May 1998, Vol.55, p. 400

abuse was involved, the ex-patient group was slightly more likely to be violent. (This may be attributable to the additive effect of psychiatric medications and other substances, or as many people with addictions describe, the lack of assistance with their addictions that is typical of psychiatric facilities, the study does not specify reasons.) Ex-patients were also no more likely to commit random violence. "The data on both targets and location of violence show that public fears of violence on the street by discharged patients who are strangers to them is misdirected".[4]

Despite the availability of this information, lobby groups and governments promote public fears in order to justify more restrictive and invasive treatment of people with psychiatric histories. The government of Ontario passed new mental health legislation they titled "Brian's Law " after Brian Smith, a man who had been killed by a mentally disturbed man. This legislation had nothing to do with addressing dangerousness. Dangerousness was covered by previous legislation. The changes allow people to be forcibly treated in the community, and if compliance with every aspect of a treatment plan is not absolute, they will be picked up by police. People can now be involuntarily admitted to a facility if a doctor believes they may mentally deteriorate at some point in the future. These extraordinary violations of the civil rights of people with psychiatric diagnoses were sold to the public by stimulating their fear, without foundation in fact. If another group named in the *Charter* was treated in this manner, it might be a more obvious hate crime. Imagine if a law restricting religious freedom was named after one member of a religion who had committed a violent crime.

Another myth is that psychiatrists can reliably predict dangerousness. This mistaken belief is relevant to the treatment of psychiatric consumers or survivors because unlike any other group in society, the opinion of a psychiatrist is considered sufficient to remove a person's liberty and right to choose. (In this respect parts of Canada allow a more arbitrary process than some other countries.) Yet there is no scientific basis for relying on these predictions. False positives are a well-established problem in risk assessments. Risk assessments of individuals fall short of predictive validity by any reputable scientific standard. Extensive hospital assessments rely on such measures as the Violence Risk Assessment Guide[5], which is able to accurately predict whether or not a person will be violent less than 20% of the time (indicated by the coefficient of determination). Clinical assessments without an actuarial guide fare even worse. What just law, or society, allows evidence without rational foundation to justify incarceration? Again, this would not be accepted but for the prejudice with which mentally or emotionally disturbed people are viewed. In this case, the misinformation is instilled by practitioners in the mental health system, although in truth many are themselves not familiar with their own poor predictive ability.

The exaggeration of dangerousness has the worst effect on people in the forensic system. (Where people who are charged with crimes go to be assessed, or are remanded following a finding of Not Criminally Responsible by reason of a mental disorder, or Unfit to stand trial.) Despite a Supreme Court of Canada ruling in *Winko* outlining the requirement that dangerousness must be proven, that the risk of harm must be real, serious, and criminal, people are held for years on minor nonviolent offenses. This is possible because prejudice is extreme toward those considered "criminally insane". Typically people serve far more time in the forensic system than they would if

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[4] ibid

[5] C. Webster et al, "The Violence Prediction Scheme", University of Toronto Press, 1996

they had simply been found guilty. Yet researchers have found that "offenders with schizophrenia were less likely than a matched control group of offenders to commit further criminal and violent offenses".[6] On top of that, "for offenders at lowest risk, evidence suggests that supervision, detention and treatment actually increase the risk of violence"[7] Clearly, discrimination dictates the fate of the men and women in the forensic system to a greater degree than any rational basis. And again, the people working in the mental health system often promote these misperceptions (e.g. unions who exaggerate dangerousness to justify job numbers and wages).

Circular reasoning makes it very difficult to shift the association between mental or emotional disturbance and violence. When a person commits a particularly violent act they are typically called "crazy", "psycho" or "sick", whether or not they were considered to be so before the act. The factors that associated with committing crimes are the same whether someone has a diagnosis or not: age, gender, substance abuse, history of abuse, etc. "In general, variables associated with psychological disturbance are poor predictors of violence and crime".[8]

Getting behind the wheel of a car with a small amount of alcohol in your system increases your dangerousness. But such people have no restriction on their liberty. Why are less dangerous psychiatric consumer/survivors legally incarcerated, while people in this condition are not? Could it be a matter of who is considered "us", who is considered "them"?

What is needed is a national educational campaign to inform the public, policy makers, people in the justice system and various professionals associated with mental health issues of the fact that we are not more dangerous than other people. Such an educational effort needs to be planned and delivered by the people this is about, as would be true of any other group, and because the medium is also the message.

2. Believing People to be Incapable

Many people believe that if you are or have been in a psychiatric hospital, if you seem mentally disturbed, you clearly are not capable of deciding what is best for you. This belief is enshrined in law in British Columbia, where involuntary patients are all treated as if they are incapable of making treatment decisions. For such a judgement to exist while having contact with real people would have to take a considerable amount of prejudice to maintain.

The MacArthur Treatment Competence study[9] found that most people considered to have serious mental illness had abilities to make treatment decisions similar to persons who were not considered to have mental illness. They concluded that their findings do not support policies that deny people the right to refuse or consent to treatment simply because people are in a psychiatric facility. They recommended screening to identify who needs help in making treatment decisions.

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[6] G. Harris and M. Rice, "Risk Appraisal and Management of Violent Behavior", Psychiatric Services, Sept. 1997, p.1170

[7] ibid

[8] ibid p. 1171

[9] P. Applebaum and T. Grisso, "The MacArthur Treatment Competence Study: I. Mental illness and competence to consent to treatment", Law and Human Behaviour, (Executive Summary www.macarthur.virginia.edu)19, 105 - 126

The provinces must overturn their legislation rooted in stereotypes of mental deficit.

In provinces such as Ontario that do a good job of separating capacity from involuntary admission, another problem arises. How are judgments made of whether a person is treatment capable? Refusing treatment, being "noncompliant" with medication is what typically precedes a person being judged by a psychiatrist as incapable. The recently publicized case of Professor Starson, heard before the Supreme Court of Canada is an example. He had been found by a doctor and the Ontario Consent Capacity Board to be treatment incapable. He described himself as being in a Catch-22. Should he say he was mentally ill, then they would say he therefore required treatment with psychiatric medications, and it would make no sense to refuse. Should he say his problem was not mental illness, they would say that proved him incapable, and they would then be able to give him medication. He wanted therapy, and found it helpful, but had found psychiatric medications to be the worst experience of his life. If the definition of capacity has no room in it for a person's own view of their problem and what they need, if adherence to the doctor's opinion defines capacity, then consent is a functionally meaningless right.

This imposition of incapacity based on "noncompliance" is discriminatory. Do mental patients alone make decisions that doctors do not like? Thousands of people with heart disease are out there making it worse, and in this instance the diagnosis and treatment are much more clearly established than in psychiatry. These people are, actually, contributing to their death, yet are permitted to do so, because they are seen as full citizens who have the right to make choices, good or bad.

People also suffer from assumptions that they are incapable in a broader sense. A person who has been mentally or emotionally disturbed enough to leave the workplace for a period of time is often treated as incapable of ever again doing adequate work. It is as if we have become something other than we were. *JB describes being dismissed when he reapplied for his job. "If I were an alcoholic, under their Employee Assistance program, they would certainly have considered all the circumstances. " He also notes that when his wife was in the general hospital she got a gift and card from the company, but being on the psychiatric ward of the same hospital, he got nothing from the company.*

Standard operating procedures in the workplace need to be rethought, as they are creating conditions that disable their employees. "The Roundtable calls for strategies to reform business practices which create employee stress including destructive office politics - a major source of mental distress among millions of "employee victims" of these behaviors."[10] But after recognizing where the fault lies, the primary change that is recommended is altering the brain chemistry of the individual "The Roundtable calls for strategies to ensure the appropriate use of prescription drugs as a principal treatment method for depression. Wrong prescriptions by physicians and non-compliance by depressed employees are major deterrents to successful treatment of the disease"[11] With no bridging logic, the problem is transformed into the faulty brained, disobedient, patient/worker.

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[10] Press release from the Business and Economic Roundtable on Mental Health, July 20, 2000

[11] ibid

Consumer/survivor run businesses have challenged the notion that people who have been in psychiatric hospitals can't work. By creating flexible and humane working environments they have not only created employment and income opportunities for the psychiatrically labeled, they can also save the government millions of dollars by reducing the number of days their employees used to spend in hospitals.[12]

3. Coercion is Required for Their Own Good

From the film "Rabbit Proof Fence"
"We face an uphill battle with these people, especially the bush natives, who have to be protected against themselves. If they would only understand what we are trying to do for them."
Mr. Neville, then Chief Protector of the Aborigines

One underlying justification for coercion is the assumption of incapacity. Another is based on the idea that there is no good reason for noncompliance with psychiatry. When people are invalidated by virtue of being mental patients, valid reasons are dismissed. This leads to denying supports we ask for, and forcing services on us that we do not want.

It is also assumed that coercion is good, because groups more powerful than the people subject to it are saying so. The experience of the terrible trauma of forced treatment recounted by many psychiatric consumers and survivors is dismissed. *DR describes this as the single most traumatic experience of her life.*
Coercion is primarily a failure of the helping relationship. In a study of people categorized as "treatment resisters", it was found that the greater the difference between the perceptions the client and therapist had of a client's problems, the more likely the person was to drop out of treatment.[13]

Some coercive practices in psychiatric facilities would be considered criminal if they were applied to people who were not first dehumanized by the label of psychiatric patient. For raising their voice, a person can be manhandled by several men, (in some facilities stripped), tied to a bed, and unwillingly injected with powerful drugs. A confession of feeling suicidal can be responded to by locking a person in a small room, with absolutely nothing to look at or do, cut off from all companionship, and often forced to relieve oneself in a pail, or on the floor. (Frequently, knocking on the door repeatedly to get staff attention for a toilet trip will result in being put in restraints for being unruly.) Accepting any treatment and thanking the staff for it is what we learn to do, and we do it, if we want to be free.

These are common occurrences, accepted because they are described as "for our own good".

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[12] 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

[13] J. Satiago et al, "The seriously mentally ill: another perspective on treatment resistance", Community Mental Health Journal, 26(3), June, p.p. 237-244

If we complain, we are seen as having no credibility. The laws of the land must be enforced in psychiatric facilities, the all too common illegal and immoral treatment of people there must be given priority. Enough independent advocates, with adequate powers, who are accountable to the psychiatric consumer/survivor community they serve, are needed in every psychiatric facility. We need a national mental health advocacy centre to share, coordinate and assist with advocacy issues. And we need education about our legal rights by c/s's, so people can better defend themselves. *(We began one such program in Ontario, and it was popular, but it has since run out of funding. There is a fledgling Mental Health Legal Advocacy Coalition consisting of consumer/survivors with experience working with the mental heal and justice systems.)*

4. Defining People as Psychiatric Diagnoses

According to Health Canada (2002), 1 out of 5 Canadians will have a diagnosis of mental illness in their lifetime. Statistics Canada reports that suicide is the eleventh leading cause of death in Canada. It is reasonable to suppose that this means everyone in Canada knows someone well who has had a psychiatric diagnosis. Yet the belief that there is an unbridgeable difference between the "sane" and the "insane" lingers on.

One reason for this is the shame and fear felt by people feel who have been in the mental health system, which leads them to conceal this experience. Similar to the gay and lesbian situation, one solution to many negative stereotypes about the community is for a greater variety of people to acknowledge their membership in it. But the sad reality is that in Canada today the price is too high for many people to do that. Ironically, the fact that so many people successfully conceal this part of their life is itself the evidence that having a psychiatric label does not render most people notably different from others.

Psychiatric diagnoses are a key component in making a disturbed person into "other". It is a myth is that they define a person, or even provide a reliable indicator to an aspect of a person. "If one looks intensively at what was identified as the core scientific problem of diagnosis in the 1970s, unreliability, one discovers that the scientific data used to claim success and great improvement (since then) simply do not support he claim."[14] The experience of people who have spent some time in the psychiatric system supports this claim. People commonly have multiple major diagnoses in their lifetime, often as many as the psychiatrists they see, some of them mutually contradictory. Scientifically speaking, an instrument that is not reliable can not be considered valid. However the entire system is set up according to these designations - treatment, social assistance, etc.

Psychiatric consumers and survivors (and, increasingly, people with addictions) are required to embrace these labels, in order to access assistance when needed. This diminishment of individuality takes its toll on people's self esteem, as it becomes part of a person's internalized oppression. This is particularly true of the hoops people are required to jump through to qualify for

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[14] S. Kirk and H. Kutchins, "The Myth of the Reliability of the DSM", The Journal of Mind and Behavior, Winter and Spring 1994, Vol. 15, No.s 1 and 2, p. 83

disability supports, where we must pronounce ourselves hopeless in various ways, and increase people's negative perceptions of us, in order to get the support so desperately needed.

Certain psychiatric labels promote more fearful attitudes than do others. "Psychopath" may be the worst in this regard. In addition it is typically a pronouncement of hopelessness from mental health professionals. The psychopath (or antisocial personality disorder) designation is subject to the same circular reasoning as dangerousness - the person commits antisocial acts - therefore they are antisocial - which is why they commit antisocial acts. People with this label also tend to be relatively young, male, with a history of considerable disruption of their life, abused, and with numerous other indicators that are independent contributors to having difficulty getting along. People given this label are often then considered incurable by mental health professionals, and as any sociologist will tell you, receiving such a label creates negative expectations that will have negative results. For the individual receiving it, this label amounts to nothing more helpful than professional name-calling. Prejudice and discrimination follow such a label. And yet people with this label do change, with the right opportunities and support. These are, however, seldom available. The forensic mental health system, for example, can be brutal, and the chance for real healing in it very rare.

The other most pejorative of psychiatric diagnoses is "schizophrenic". In popular parlance this word is used as a stand in for "craziness", dangerousness - it renders the person irretrievably "other". Psychiatrists typically tell people who are so labeled that they have a prognosis of lifetime illness, which can be controlled only through medications. When people are told they have schizophrenia, they are typically taught to relinquish ideas of significant achievement in life. *B was told: "you will only get worse".* Should a person then commit suicide, this is attributed to their mental illness. For many years psychiatric survivors have denounced the psychiatric practice of conveying this information to people. "It is not true" said people who had received this same news, but gone on to lead full lives. *I have heard this point made by c/s's on a number of committees. They are typically denied in the same way - by someone stating the person had just been misdiagnosed, that they were the exception to the rule.* When we provided research to support our perspective it had no effect. We arranged for well-respected academics to speak in public forums to describe their findings (e.g. that most people who receive this label of schizophrenia will end up better off then they are at that time.[15]) Almost no mental health professionals attended. Finally, the word "Recovery" has developed as a buzzword in the U.S, and has caught the attention of some Canadians in the mental health field. There is no acknowledgement to consumer/survivors of our truth, and their decades long error. And there is no decision to have the consumer/survivor voice included in all educational programs. There are now mental health professionals who are paid to talk about recovery. But it is a step forward that some professionals might not tell people that the best they can ever hope for is symptom management.

Sadly, real descriptions of people take a back seat to the practical purpose of these stereotypes of people - which are needed for doctor's billing practices.

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[15] C. Harding et al, "The Vermont Longitudinal Study of Persons with Severe Mental Illness, I: Methodology, Study Sample, and Overall Status 32 Years Later", American Journal of Psychiatry 1987, 144:6, 718 – 726

If supports were based on needs and abilities rather than derogatory labels, the process of getting support would promote self-knowledge and empowerment. Recipients of services (e.g. in consultations held at the Centre for Addiction and Mental Health) have stated that it would be more respectful and empowering to name the types of supports and services that are available, so that they can access what they most need. When services are through diagnosis based programs which have limited meaning and contain many assumptions, the chance that they will be the right fit for a particular individual get smaller. The over reliance on diagnoses allows mental health professionals to emphasize their role as expert, and devalue a person's expertise on their own life and needs. This problem has its roots in a mental health system that has developed as if it is equivalent to physical medical care, with concrete tests for specific illnesses. As long as the myth of equivalence persists, the knowledge of the consumer/survivor will be devalued.

5. Silencing Our Stories with Excessive Biomedical Explanations

We live in an era when people who are different, who are having difficulties of a mental or emotional nature, are all called "ill".

Most people in the psychiatric system are survivors of abuse[16]. Many people will be abused while in the psychiatric system.[17] For decades psychiatric survivors have been speaking these truths. But our voice has been drowned out by people with power and a vested interest in the predominance of biomedical explanations for human suffering.

Abuse is an overwhelming presence in the lives of most psychiatric consumers and survivors. The magnitude of the effort involved in ignoring abuse as a cause of distress, and failing to respond to its effect[18], would be difficult to understand if one did not recognize the ability of the powerful to define what is real in psychiatry. Should people's mental and emotional distress not have a primary origin in organic brain dysfunction, the entire system as it exists today would be called into question. Psychiatrists would not necessarily be considered the foremost expert in the mental health field. Powerful family lobby groups that have denounced survivors and others who have raised such issues would have their bias called into question. No wonder it has been so difficult for survivors to simply be heard, on an individual and systemic level. If we were heard and believed, this would disrupt others greatly.

X, a man in the forensic system right now, has been asking for help for over 20 years with his history of having been sexually abused. He has not received it. He is described simply as being

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[16] J. Bryer et al, "Childhood Sexual and Physical Abuse as Factors in Adult Psychiatric Illness", American Journal of Psychiatry, 144:11, Nov., 1987, p.p. 1426-1430
L. Craine et al, "Prevalence of a History of Sexual Abuse Among Female Psychiatric Patients in a State Hospital", Hospital and Community Psychiatry, march 1988, vol. 39, No. 3. P.p. 300 - 304
T. Firsten, “Violence in the Lives of Women On Psych Wards, Canadian Women Studies, Vol. 11, No.4, p.p.45 - 48
A. Jacobson and B. Richardson, "Assault Experiences of 100 Psychiatric Inpatients: Evidence of the Need for Routine Inquiry", American Journal of Psychiatry, July 1987, p.p. 908-913

[17] D. Nibert el al. "Assaults Against Residents of a Psychiatric Institution", Journal of Interpersonal Violence, Sept 1989, p.p. 342-349.

[18] Craine, ibid; Firsten, ibid

"noncompliant" with medication. And L has at various times had all the major psychiatric labels, with little to no recognition or support for herself as an abuse survivor (a continuation of the environment of silence in her family).

There has been some progress made - there has been some recognition that some women in the mental health system need some trauma counseling, but it is extremely limited. Male abuse survivors can have even more difficulty getting real help because of the social bias that males seldom get abused. And there is also some "fear that a system so entrenched in punitive ways will not be able to incorporate the kind of work necessary to heal from trauma".[19]

Addiction services have often done better than psychiatric services at offering holistic, egalitarian supports that assist people in finding new ways of coping without substance use. The lived experience of addicts in recovery is recognized as a valuable quality in staff. However as mental health services have become more involved with addiction services, these precious qualities are threatened. Some people benefit from the link by not falling between the cracks, excluded from supports on both sides. But there are also complaints that with the presence of psychiatry, people with addictions are now being encouraged to rely on substances (prescribed medications) instead of learning other ways to cope. And the egalitarianism is being eroded that is so helpful for self-esteem and learning by example.

If people's prior experience of abuse and trauma is ignored, imagine the difficulty we have being heard and believed when we report our experience of abuse within the psychiatric system. "Despite the vulnerability of clients and the apparent prevalence of abuse, the effects of abuse of clients by professionals has attracted little attention in the literature."[20] Sadly, the experience of abuse in the psychiatric system is not rare[21], but prosecution is almost unheard of, because prejudice so easily allows c/s's to be seen as having no credibility. This prejudice toward our credibility extends throughout the justice system.

The drowning out of the c/s voice by the emphasis on the medical model is not limited to abuse issues, but these issues are a demonstration of the harm caused by invalidating a people's voice, and allowing those in powerful positions to define what is true of other people.

In Ontario, people with limited economic means are the greatest victims of the dominance of the medical model. With few exceptions, only treatment with people with medical degrees is covered by public health insurance. As a result those with the least money are most likely to end up on psychiatric drugs, and are more vulnerable to involuntary processes that only doctor's can legitimize.

Homelessness is often blamed on deinstitutionalization, on the mentally ill wandering free. Evidence does not support this theory. Research does suggest that homelessness causes people

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[19] National Association of Consumer/Survivor Mental Health Administrators (NAC/SMHA), "The prevalence of abuse histories in the mental health system", www.nasmhpd.org p.1

[20] Kumar S. Client empowerment in psychiatry and the professional abuse of clients: Where do we stand? International Journal of Law and Psychiatry 2000;30(1): p. 65

[21] D. Nibert el al, ibid

to become mentally disturbed far more than the other way around.[22] Furthermore, homeless people need homes more than they need mental health services.[23]

The biological explanation for all our distressing thoughts and feelings has predominated not because it has been proven to be true[24], but out of both good intentions and support for the status quo. The good intentions behind the illness model are to relieve the individual and the family of blame. Truly blame is not helpful, but it should not be avoided at the cost of the truth, and compassion and understanding are better substitutes for blame than an overblown metaphor of illness. Attributing most distress to brain malfunction is intertwined with the status quo. If it is the brain at fault, family (or other relationships that involve authority figures) need not be examined, and the cycle of abuse stopped; social inequities that are determinants of health can be overlooked; the people who benefit from the current structure of the mental health system can retain their power. But we can only truly heal when our truth is known, so we need a system of support that is not biased against our truths.

We repeat this important fact. No consistent brain dysfunction has been established as a cause of "schizophrenia", "depression", "personality disorder" - any of the psychiatric diagnoses. [25]

Consumer/survivors' stories and understanding of ourselves need to be heard. Information and theories from others are welcome, we are not seeking our liberation from silence by silencing others. We are complex, and there will be many and varied explanations for how we became who we are today: life experience, economics, biology, etc. The cause and effect circle between the mind and the brain has yet to be defined. The invalidation of consumer/survivors by imposing one model on all our stories must end.

6. Who Decides what We Need? The Selling of the Pharmaceutical Solution

"Follow the money" it is often said, if you want to find out why who does what. Psychiatric survivors have been called hostile, paranoid, delusional and other psychiatrically based epithets for pointing out the bias in the mental health system generated by the enormous financial influence of pharmaceutical companies. Recently more people have noticed this bias. David Healy and Nancy Olivieri are academics and researchers who had work taken from them following their raising of concerns about the dangers of some medications. Angell, former editor of the *New England Journal of Medicine* called for codes for conflict of interests. The *Journal* disclosed it had published

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

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

[24] A. Siebert, "Brain Disease Hypothesis for Schizophrenia Disconfirmed by All Evidence", Ethical Human Sciences and Services, Vol 1, No. 2, 1999, p.p. 179 - 189
D. Antonuccio et al, "Raising Questions about Antidepressants". Psychotherapy and Psychosomatics 1999, 68:3-14

[25] Siebert, ibid, Antonuccio, ibid
S.Chua, and P. McKenna "Schizophrenia-a Brain Disease? A critical review of structural and functional cerebral abnormality in the disorder" Brit. Jour. Psych., 1995, 166: 563-582.
K. Zakzanis et al "Searching the Schizophrenic Brain for Temporal Lobe Deficits: a systematic review and meta-analysis" Psychol. Med., 2000, 30: 491-504.

19 articles on drug treatments without revealing the authors' links with the drug industry. Shortly after this revelation the M. Angell was replaced as editor with J. Drazen - who had accepted grants or an advisory role at eight companies.[26]

No consultation with consumer/survivors has ever generated the information that consumer/survivors think they do not get enough psychiatric medication. For years a hospital based consumer/survivor advocacy group was told by its membership to demand that the over use of medications must stop. The response from the hospital never varied - medications are not over used. And yet the dosages that patients received far exceeded the amounts recommended in the literature. Pharmacists acknowledged the medications the doctors were prescribing were higher than recommended. The people on the receiving end of the drugs constantly complained of how sick and drugged they felt. Years later, at huge expense, the hospital used PET scans to discover that drug doses were too high, and this was a much vaunted research success. Please try to imagine the people who suffered and died while their voices went unheeded, because they were not "expert" enough to challenge medical practices.

Psychiatric medications have been very successfully sold as a necessity for anyone with a psychiatric label, or anyone in any distress. On an individual level this often takes place by prescribing doctors failing to meet the legal requirements for informed consent. On a social level this assumption has been ingrained by various means. The facts are that psychiatric medications have a limited effectiveness. The effectiveness of neuroleptics in delaying rehospitalization relative to a placebo is approximately 34%. Evidence suggests that neuroleptics are equivalent to a placebo or simple sedative for bringing agitation under control.[27] Antidepressants have an effectiveness rate compared to that of a placebo of between 8 and 25%.[28] We mention this research because countless self-reports in which people have said that the drugs are not helping have been dismissed as "lacking in insight".

Worse still than being forced to take medications that do not help is being permanently damaged by these drugs without having been informed of this risk. People who have chosen to take medication and have found it to be helpful still do not appreciate not having been warned of the lasting harm that often results. Psychiatric medications can cause brain damage, death, cause violence and suicidality, permanent and disfiguring tics, tremors and twitches, a feeling of being tortured from within, unbearable restlessness, sedation, significant weight gain, dizziness, inability to tolerate heat, destruction of the immune system, withdrawal effects, etc. [29] A number of characteristics that many people (including the person receiving the drugs) identify with being "crazy" are actually side effects of medication. It is almost unheard of for people to receive

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[26] J. Donn, "Drug Studies Tainted" Toronto Star, May 18, 2000

[27] D. Cohen, 1997, "A Critique of the Use of Neuroleptic Drugs", in S. Fisher & R. Greenburg From Placebo to Panacea: Putting Psychiatric Drugs to the Test. New York: John Wiley and Sons

[28] R.Greenberg et al, "A Meta-Analysis of Antidepressant Outcome Under "Blinder" Conditions". Journal of Consulting and Clinical Psychology 1992, Vol. 60, No.5, 664-669
D. Antonuccio et al, "Raising Questions about Antidepressants". Psychotherapy and Psychosomatics 1999, 68:3-14

[29] J. Ballesteros 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/No 2, April 2000, p.p. 188 - 194
Cohen, ibid
P. Sachdev et al, "Negative Symptoms, cognitive dysfunction, tardive akathisia and tardive dyskinesia" Acta Psychiatria Scandinavica, 93, 1996, p.p. 451-459

information about these risks, despite it being required by law in Ontario that they receive this information. Despite the outcry against this practice by consumer/survivors the situation does not change. How can the law be enforced when the word of the complainant, the person receiving the drugs, is perceived to be of little value relative to that of the person dispensing the drugs?

We have begged for inquests into the deaths of people who have died of symptoms common to the drugs they were taking, but the coroner's office has held no inquests into these deaths. How little our lives seem to matter compared to professional reputations.

"Currently, politically and financially powerful forces oppose any consumer/survivor change to the existing mental health system. However the system *must* change."[30] People who have lived the psychiatric system in Canada need your help to find a way to do it.

What We Need

RECOMMENDATIONS

1. **A national education program - a campaign directed and delivered by consumer/survivors needs to be launched to challenge the devastating prejudice and discrimination that is directed at our community.** The false beliefs and faulty practices we described in our submission must be addressed by good information. This needs to be done for the public, justice system, mental health system, policy makers, and consumer/survivors (who suffer the internalization of prejudice).

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[30] National Disability Council, ibid

2. **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.** 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.

3. **Each psychiatric facility must have independent advocacy available to consumer/survivors, and an established avenue for the consumer/survivor voice at the facility, accountable to c/s's .**
   (The Empowerment Council and the Centre for Addiction and Mental Health have agreed to have both.)

4. **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.

5. **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.[31]

6. **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" is an international c/s slogan.

7. **The standards for hate crimes should be equivalently applied to crimes against persons who are considered to have a mental disability.**

8. **Income assistance must reach rates that allow persons on disability to lead healthy lives and participate in society.** 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.[32]

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[31] 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

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

9. **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.** As with the independent living approach in use by people with physical disabilities, the funding should follow the individual so she/he is able to access what is most needed.

10. **Real choices must exist in the mental health system for services to be effective.** 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.[33] A national research council consisting of academics and consumer/survivors needs to be formed to examine best practices outside of the current system "box".

11. Apply the following excerpt from report of the Standing Senate Committee on Social Affairs, Science and Technology to mental health services:

    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.

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[33] 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.