A Reason to Hope. The Means to Cope.
British Columbia Schizophrenia Society
BC Schizophrenia Society Foundation
Supporting the BC Schizophrenia Society

August 29, 2014

Dr. David Goldbloom, Chair
Mental Health Commission of Canada
#320 – 110 Quarry Park Boulevard SE
Calgary, Alberta T2C 3G3

Dear Dr. Goldbloom,

Re: *Declaring our Commitment to Recovery*

The BC Schizophrenia Society is appreciative of the work the Mental Health Commission of Canada (MHCC) has done to assist people with mental illness on their path to recovery. The BC Schizophrenia Society is also committed to recovery.

Our mission is to improve the quality of life for people affected by schizophrenia and psychosis, and our organization is engaged in a number of recovery activities. However, many people come to us seeking support for adult relatives who are delusional due to a psychotic illness and who have chosen not to seek voluntary treatment.

We must be able to assure family caregivers that the MHCC's model of "recovery" includes the needs of their loved ones who, because of their illness, may not always be able to direct their own care. We would appreciate a response to the following questions so that the BC Schizophrenia Society can confidently promote the Mental Health Commission of Canada's "recovery declaration."

1. **"Recognizing that each person is a unique individual with the right to determine his own path towards mental health and wellbeing."**

   There are many people with untreated schizophrenia, including several who have been involved in high profile incidents, who do not recognize that they have a treatable brain illness. Nor does their illness let them understand the likelihood of serious harm to themselves or others if they do not receive treatment. *Does the MHCC recovery model include ill people whose judgment is impaired, even though they cannot "determine their own path towards mental health and wellbeing"?*

2. **"Recovery is a process in which people living with mental health problems and illnesses are actively engaged in their own journey of wellbeing."**

   Each year, there are approximately 60,000 involuntary psychiatric admissions in Canada. In most cases, attempts have been made to engage the ill person to voluntarily accept services, but to no avail. By definition, they have not engaged in "their own journey" because hospital care was imposed on them and they did not "self-direct" it. *Are the most vulnerable people with the most severe disorders excluded from the MHCC version of recovery? If not, how is their recovery represented?*

3. **"Recovery principles—including hope, self-determination and responsibility—can be adapted to the realities of different life stages, and to the full range of mental health problems and illnesses."**

First-break Psychosis
Many people with first-break psychosis do not recognize that they are ill. It is hard to grasp how the concept of "hope" is relevant to someone who thinks nothing is wrong with them. Similarly, how can a person with first-episode psychosis exercise "self-determination" while experiencing delusions and hallucinations which they believe are real? Left to "self-determine" many would continue to suffer from untreated psychosis and would have a very poor prognosis. It is difficult to understand how a person in psychosis, especially early psychosis, has a "responsibility" to get well, as the MHCC model requires. *Are first-break psychosis patients excluded from the MHCC model?*

NCRMD
Each year a large number of people in Canada are judged "not criminally responsible on account of mental disorder" (NCRMD). *Since "self-determination and responsibility" are important recovery principles, does the MHCC model exclude NCRMD patients until they have been treated and are then deemed to be "responsible" for their own care?*

In short, the current MHCC recovery model appears to exclude (i) people who are severely ill and require involuntary treatment; (ii) people who commit a crime because of their illness; and (iii) people who are experiencing first-episode psychosis.

We would appreciate an explanation as to how the current MHCC recovery model addresses the issues we have raised, *or*, whether there might be some supplementary principles recognizing the fact that treatment for psychosis is necessary before a person can "self direct" — so that the model actually includes the needs of this vulnerable population.

Finally, we would like to bring your attention to the following:

"Families are best able to contribute to the recovery of their loved ones when their own needs are recognized and they are supported in their own journeys of recovery."

The above sentence seems to imply that families of people with schizophrenia are themselves unwell or have mental health problems. This may not be the intended meaning—but the concept is misunderstood by many family members, who are confused by word usage that conflates two different meanings. *It would be very helpful if the MHCC could clarify the meaning of "recovery" as it applies to the family unit, i.e., understanding and coping together as a family, adjusting plans and expectations as necessary, and so forth.*

Thank you once again for all the good work that you do. We look for to receiving a reply regarding these matters at your earliest convenience.

Sincerely,

David Halikowski
President

Mental Health Commission of Canada
Commission de la santé mentale du Canada

December 11, 2014

David Halikowski, President
BC Schizophrenia Society Foundation
#210 -6011 Westminster Hwy
Richmond BC V7C 4V4

Dear Mr. Halikowski:

Thank you for your letter in which you raise a number of important questions family caregivers have regarding the principles contained in the Recovery Declaration.

I sincerely apologize for the delay in responding. My colleague, Jennifer Vornbrock, Vice-President of Knowledge and Innovation at the Mental Health Commission, had hoped to set up a meeting with you and members of your medical advisory board for a dialogue about the issues you raise and explain our understanding of how recovery principles do in fact respond to your concerns.

I am still hoping such a dialogue can occur when I am or she is next in Vancouver. I was with Bill Honer at the Pacific Rim College of Psychiatrists meeting in Vancouver recently but we didn't have an opportunity to discuss this. However, in the interim, I would like to take this opportunity to respond briefly to your questions.

In your letter, you cite four sets of circumstances that seem to challenge the validity of the Recovery approach:

1. When people are not aware that they have a treatable illness
2. When people have had to be involuntarily admitted to care
3. When people are experiencing first-break psychosis
4. When people have been declared NCRMD

You link these to specific elements of the Recovery approach that we outlined in the Recovery Declaration, all of which address the importance of supporting people to take charge of their own journey of recovery. The key issue is whether recovery principles can still apply in circumstances where a person's decision-making capacity is impaired or restricted.

As a clinician who has worked in inpatient, emergency and outpatient care in a hospital for the last 30 years, I am directly familiar with patients who have found themselves in all four of the scenarios you have described.

I think it is the idea of recovery as a "journey" that captures our understanding of how the recovery approach is still relevant, even during challenging times. First, let me state that a recovery approach to care acknowledges that mental health problems and illnesses can be

episodic or sustained and there may be times when people do not recognize that their behaviours and symptoms need attention, or they lack the capacity to make important life decisions. A recovery orientation does not at all preclude the need for laws and policies that ensure that people who are a danger to self or others are kept safe and are able to receive the treatment and services they need to support them in getting well.

However, whenever decision-making responsibility is withdrawn, an important recovery goal is to support people to regain decision-making as quickly as possible. The recovery "journey" is seldom a linear one, and can be marked by detours and setbacks that can require varying types of intervention by family and the mental health system. Nonetheless, the concepts of self-determination, personal responsibility and self-management, and the goals of reclaiming control and choice remain pivotal regardless of a person's health situation or legal status. Recovery principles emphasize the importance of working collaboratively with a person and their family irrespective of whether they are receiving treatment voluntarily or involuntarily, or whether that treatment is in a hospital or in the community.

There are also a variety of measures that can be employed to help address the twists and turns in a person's recovery journey. The development of advance directives, for example, provides an opportunity for open, transparent and honest discussion of perceived risk and safety planning. They can provide guidance to mental health providers in protecting peoples' rights and in keeping their values and wishes at the forefront during a crisis. A follow-up review of steps taken to manage the crisis can help people negotiate a preferred course of future action and identify skills and resources they may need to identify risks and manage potential problems down the road.

I hope this clarifies our perspective, and Jennifer and I look forward to discussing this with you in person.

Sincerely,

David S. Goldbloom, OC, MD, FRCPC
Senior Medical Advisor,
Centre for Addiction and Mental Health
Professor of Psychiatry, University of Toronto
Chair, Mental Health Commission of Canada

Cc: Jennifer Vornbrock

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January 07, 2015

Dr. David Goldbloom, Chair
Mental Health Commission of Canada
#320 – 110 Quarry Park Boulevard SE
Calgary, Alberta T2C 3G3

Dear Dr. Goldbloom,

RE: Declaration of Recovery

Thank you for your response of December 11, 2014 to our concerns about the Mental Health Commission of Canada's *Declaration of Commitment to Recovery*. We would be very pleased to meet with you when you have an opportunity to visit B.C.

Your letter reflects your comprehensive clinical experience, and your understanding that the principles of recovery apply even to individuals who are unaware that they have a treatable illness, those admitted to involuntary care, and those who are found not criminally responsible because of a mental disorder.

Unfortunately, the MHCC Recovery Declaration as it stands does not reflect the insights you offer from your own extensive experience. There are no caveats to the Recovery Declaration's stated principles regarding incapability or involuntary status. Instead, an individual is only said to be included in the MHCC "Recovery" group when he or she has "the right to determine his/her own path towards mental health and wellbeing."

Or, to consider another non-nuanced principle: "Recovery starts with hope, optimism, and the fundamental belief that recovery is possible." Without further explanation, this statement excludes many people from the MHCC recovery model—including approximately 3500 Canadians who commit suicide each year and 75,000, who attempt it. In fact, many severely depressed people have no hope or sense of recovery—and are thus, by definition, outside the scope of the MHCC statement. But they can and do respond very well to treatment, and do recover.

It appears to us that the MHCC Recovery Journey begins too far down the track. The BC Schizophrenia Society (BCSS) is more interested in a Comprehensive Recovery Model, a model that can help individuals begin the recovery journey even if their symptoms preclude them from doing so on their own. According to the MHCC, recovery can only start when the person is able to direct their own journey.

The thrust of our concern is that the MHCC recovery position as currently stated is misleading. People not familiar with a comprehensive recovery movement including treatment, rehabilitation, and other necessary resources may be misled into thinking that treatment services vital to actual recovery are not needed. Government funders, for example, may believe that professional services are not required

for recovery to happen, and that providing peer counselling, having the individual take personal responsibility, and so on will suffice.

We are also very concerned about your statement that people "who are a danger to self or others are kept safe," which seems to imply that these are the criteria for involuntary admission. The BC Schizophrenia Society and other Schizophrenia Societies across the country have battled that concept to help make treatment more accessible and reduce stigma against people with untreated mental illness. It is important to accurately reflect committal criteria in Canada. In British Columbia, Alberta, Saskatchewan, Manitoba, Nova Scotia and Newfoundland and Labrador, committal criteria include "harm" (broadly interpreted to include more than physical danger) and/or "substantial mental or physical deterioration." Even Ontario has one stream that accepts people who are not dangerous but likely to deteriorate. BCSS has invested a great deal of effort and resources into advocating for this issue.

We of course agree that regaining decision-making capacity as quickly as possible is a goal everyone supports. However, while advance directives can give guidance to mental health providers, we know that they are not widely used, especially by people with first break psychosis, those whose illness causes lack of insight, or causes them to commit crimes or suicide.

In promoting advance directives, the MHCC should also point out the danger to patients who can unwittingly refuse the very treatment they need to regain their health and be released from detention. In Ontario, advance directives caused Mr. Sevels to be kept in seclusion for over 404 days because he could not be treated for his treatable schizophrenia. Professor Starson was incarcerated for 5 years and almost died from delusion-induced starvation because of his own advance directive. Others have spent more than 10 years in hospital because their advance directives specifically refused medical treatment. Details of these tragedies are available in a paper published in the McGill Law Journal, "Treatment Delayed Liberty Denied."[1] Dr. Thomas Szasz, who denies the existence of schizophrenia and other serious mental illness, is a strong proponent of patients making advance directives to refuse psychiatric treatment.

Our letter also expressed concern with the wording that families are "supported in their own journeys of recovery," implying that families are "recovering" from mental health problems or mental illness. This is a position we reject and would appreciate your comments on.

We should also mention that we appreciate the MHCC Recovery Library, which contains books about recovery in schizophrenia, including lack of insight, and successful involuntary treatment.

In summary, we greatly value your work on this issue. We believe that an addendum or other document that addresses our concerns would be helpful. Since we know how important treatment is for serious mental illness, we would encourage the MHCC to adopt a Comprehensive Recovery Model that includes all aspects of recovery.

Sincerely,

David Halikowski
President

[1] Solomon, R., O'Reilly, R., Gray, J. and Nikolic, M. "Treatment Delayed – Liberty Denied". Canadian Bar Review, 87:679-719.