REASONS FOR HOPE

VOLUME 20, NUMBER 3, Winter 2009 MANITOBA SCHIZOPHRENIA SOCIETY NEWSLETTER

Mental Health Commission of Canada to engage Canadians about draft framework for developing a comprehensive mental health strategy

By Chris Summerville, Executive Director, Manitoba Schizophrenia Society

During the months of February and March, the Mental Health Commission of Canada will be engaging Canadians in a discussion about the principles or goals of a national mental health strategy. Through on-site and on-line consultations, the Commission wants to hear from Canadians about the eight proposed goals as articulated in its framework document, TOWARD RECOVERY & WELL-BEING.

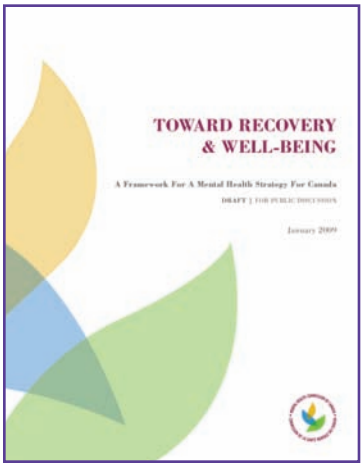
I am encouraging MSS constituents to let their voices be heard! You can find out more information about the on-line consultation at www.mentalhealthcommission.ca.

This issue of Reasons for Hope focuses on stigma and discrimination. The seventh goal proposed by the Commission is about these two things. I have heard many people say that living with the social prejudice towards those with mental illness is worse than living with the mental illness!

MSS is committed towards working with the Mental Health Commission of Canada in transforming our mental health system into a recovery oriented system. Included in our advocacy message is the elimination of stigma and discrimination towards those with schizophrenia and psychosis. You can help us by participating in and telling others about the on-line consultation!

Toward Recovery & Well-Being

Toward Recovery and Well-Being is the first document to be released for public discussion by the Mental Health Commission of Canada. We are excited at the prospect of engaging Canadians in a dialogue about transforming the mental health system in our country.



This document presents a draft framework for developing a comprehensive mental health strategy for Canada. The eight goals set out provide a vision for WHAT a transformed mental health system should look like – one that can both foster recovery for people living with mental health problems an illnesses, and promote the mental health and well-being of all Canadians.

We invite your comments on this draft framework (please follow the links at www.mentalhealthcommission.ca). Once it is finalized, we will move on to the second phase of developing a mental health strategy – producing a detailed roadmap for HOW the eight goals can be achieved.

For this process to be a success, input will be required at each stage from Canadians from coast to coast. There is much to be done but, judging by the many signs of growing public interest in mental health issues, the momentum for change is building.

Working together, we will be able to transform our current mental health system and enhance the mental health and well-being of all Canadians. Most importantly, we can – indeed, we must – improve the health and social outcomes for those living with mental health problems and illnesses, as well as their families.

It is up to all of us to ensure that mental health issues stay out of the shadows – forever.

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While all of the goals are important, I would like to single out proposed goal 7:

DISCRIMINATION AGAINST PEOPLE LIVING WITH MENTAL HEALTH PROBLEMS AND ILLNESSES IS ELIMINATED, AND STIGMA IS NOT TOLERATED.

People living with mental health problems and illnesses, along with their families, are fully included in community life. They are accorded the same respect, consideration, rights and entitlements as people dealing with physical illnesses and as all Canadians, and mental health service providers are similarly respected. Mental health programs and policies are funded and supported at a level that is based on the economic and social burden of mental health problems and illnesses and is consistent with the funding provided to the rest of the health and human services sectors.

Background

- Stigma and discrimination have a huge negative impact on people living with mental health problems and illnesses, affecting all aspects and stages of their lives – dealings with friends, family, educators, employers and the health care system itself.
- Stigma refers to beliefs and attitudes about mental health problems and illnesses that lead to the negative stereotyping of people living with these problems and to prejudice against them and their families.
- There are many forms of discrimination: it can be overt and direct, involving the exercise of power over people, and it can also be passive or "structural," meaning that it is reflected in policies, practices and laws.
- Forms of discrimination also occur within the health care system itself, and people working within the health care system are not immune from having stigmatizing attitudes.
- When internalized, self-stigma can cause people with mental illnesses to become isolated from others and avoid taking on new challenges.
- The most effective anti-stigma strategies are targeted at specific populations or settings and encourage direct contact with people living with mental health problems and illnesses.
- Great progress has been made in eliminating many forms of discrimination and stigma associated with other illnesses.

Key Principles

- People living with mental health problems and illnesses, and their families, should be given the same respect, consideration, entitlements and rights as people dealing with physical illnesses and as all Canadians.
- People living with mental health problems and illnesses who access social programs should be treated in a comparable fashion to other Canadians who rely on these programs.
- Mental health service providers must be recognized and respected for the valuable role they play.

In a transformed mental health system:

- Discrimination against people living with mental health problems and illnesses will be eliminated and stigmatizing and demeaning attitudes and language will not be tolerated.
- Mental health programs and policies will be funded and supported at a level that is based on the economic and social burden of mental health problems and illnesses and is consistent with the funding of the rest of the health care and related human services sectors.
- Workplaces, schools and other community settings will create an atmosphere that is open, accommodating and supportive of people living with mental health problems and illnesses.
- Changing attitudes and behaviours towards people living with mental health problems and illnesses is a challenge that is taken up by all Canadians on a daily basis. ■

Stigma Defined…

Stigma

- Is an indelible mark, brand, or label, and
- Connotes a moral judgment conferred on an entire class of people

Resulting in…

- Spoiled social identity
- Inferior social status
- A denial of humanity
- Inequitable and discriminatory treatment

Stigma: The Hidden Killer

People who live with mental illness and their families often state that the stigma associated with their diagnosis was more difficult to bear than the actual illness. Stigma is all-encompassing. It affects the ability to find housing and employment, enter higher education, obtain insurance, and get fair treatment in the criminal justice or child welfare systems. Stigma is not limited to the attitudes and actions of others. Self-stigma relates to internalized negative stereotypes that lead people with mental illness and their families to adopt attitudes of self-loathing and self-blame leading to a sense of helplessness and hopelessness.

Stigma is dangerous because it interferes with understanding, obtaining support from friends and family, and it delays getting help (sometimes for years). **Stigma is:**

- An inhibitor of primary prevention
- A fundamental cause of disease (marginalization, oppression and denial of opportunity)
- A factor that limits early detection
- A factor that interferes with positive treatment outcomes
- A contributor to a drain on health resources and on the Canadian economy
- An impediment to recovery
- Multi-faceted and creates a multiplier effect (stigma piled upon stigma).

Theories about why people stigmatize involve ideas about humankind's natural protective responses to perceived threats and social processes that tend to identify and categorize human difference, leading to decisions regarding which individuals or groups are valued and which are not. The exercise of power is central to stigma - overtly to reject and exclude or covertly to devalue and discredit.

New directions for health-related stigma research suggest initiatives that document the burden of stigma, compare stigma among health problems, define the determinants of stigma, develop measurement tools and implement research methods that include consumers and families in research.

While consumers and families value research, they also tend to focus on this as it relates to action. Having experienced stigma first hand, they are interested in what, exactly, to do about it.

Research regarding anti-stigma interventions offers mixed results. Public attitudes and behaviours are extraordinarily resistant to change. In addition, most anti-stigma campaigns are un-evaluated, time-limited, and piecemeal, depend on volunteers and are mounted with limited budgets. Some anti-stigma approaches that have potential:

Counteracting self-stigma

- Empowerment (self-help and peer support groups, economic development programs, Mad Pride parades, advocacy)

- Recovery (personal growth and healthier choices leading to improved quality of life)

Changing public attitudes

- Anti-stigma campaigns that involve positive contact with people with mental illness and their families (print ads, television, films, seminars and presentations)
- Media-watches to expose biased reporting or negative stereotyping
- Laws and policies that prevent discrimination
- Tests and surveys that encourage people to self-identify and get help
- Self-expression through the arts which celebrate people's talents while, often, providing educational or advocacy messages.

This overview paper concludes with recommendations for future Canadian research directions that have particular resonance for consumers and families:

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Stigma: The Hidden Killer

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1. Self-stigma is the enemy within. It renders a person complicit with the injustice of externally imposed discrimination and stereotyping. Yet the processes by which people come to believe that they deserve ill-treatment and ostracism are ill defined. As result, mechanisms to counteract self-stigma are less well articulated. There is a rich source of ideas in the recovery movement that require further thought and, perhaps, re-framing in terms of the mechanisms that address the effects of self-stigma. Recovery, along with self-empowerment, may be among the premiere antidotes to self-stigma because they change one's own ideas about self and the world. **Self-stigma is an important area for further research.**

2. Anti-stigma campaigns are aimed at changing others' attitudes and beliefs. The sheer amount of activity offers many useful examples about what works, and what does not. In Canada, there is no need to re-invent the wheel. The time has come for action. Consumers and families are less concerned with measuring the extent and impact of stigma (they already know that). **Research attached to action would be highly valued.**

3. **Consumers and families must be involved**, not only in defining the actions to be taken and delivering the resulting campaigns, but also in the complete research process. They must participate in developing the research questions, collecting data and in analyzing results. No one cares more than they do about outcomes. As a result, they are the funders' best allies because they, too, want to ensure that investment pays off.

4. Often research, like many of the anti-stigma campaigns, can be piecemeal and unconnected. People don't hear about results and thus, are unable to make use of what has been learned. **Consumers and families have active organizations that can be utilized for the dissemination of both the campaigns and the research findings.**

Consumers and families recognize all too clearly that stigma can kill. They have a sense of urgency driven by personal experience that can be used to fuel change. However, changing attitudes and behaviours is extraordinarily difficult. While there is a lot of activity focused on anti-stigma campaigns and, while there is some evidence that beliefs are shifting, there is much work left to do.

(Full report can be found at http://www.mooddisorderscanada.ca/ under "Publications.")

Why Does Stigma Exist?

By Neasa Martin,
Advisor to Mental Health Commission of Canada

"A mark of shame, disgrace or disapproval"

Three inter-related problems:

1. Lack of knowledge ==> (ignorance)
2. Negative attitudes ==> (prejudice)
3. Excluding/avoiding behaviours ==> (discrimination)

Three variants:

1. Health-related stigma (based on specific condition)
2. Self-stigma (internalized, self-limiting)
3. Courtesy stigma (families, health care providers)

Stigma builds on:

- Repeated exposure to misinformation reinforcing negative perceptions
- False beliefs are intensely held and enduring
- Results from fear and mistrust of differences

– Media plays a critical role

Impact of Stigma

Stigma impacts every area of life:

- Leads to discrimination - very real
- Impacts employment; housing; social exclusion; poorer health care (decreased life span), policy and funding neglect; coercive treatment; denial of basic human rights
- Stigma is experienced as disrespect and as a barrier to social inclusion

– Emerging focus - to look at discrimination, social inclusion & rights

– Stigma focuses on attitudes ('stigmatized')

– Discrimination focuses on the behaviours (those who 'stigmatize').

Don't Call Me Nuts: Beating the Stigma of Mental Illness

by Dr. Patrick Corrigan Illinois Institute of Technology

We have to change public stigma!

Myth: People with serious mental illness are dangerous.

Fact: People without mental illness are more dangerous especially when using drugs or alcohol.

Myth: Serious mental illness is rare.

Fact: Schizophrenia makes up 0.8% of the population. In Chicago Metro, that is 64,000 people, or the population of Joliet, Illinois.

Myth: People with serious mental illness cannot care for themselves and they need to be institutionalized.

Fact: Long term follow-up research suggests two-thirds of people with schizophrenia learn to live with their disabilities.

Myth: People with serious mental illness are only able to work in menial jobs.

Fact: Nothing about serious mental illnesses should stop people from accomplishing any profession. They are doctors, lawyers, writers, actors…etc.

Myth: People with serious mental illness are responsible for their problems.

Fact: People with serious mental illness do not choose their symptoms or disabilities.

"Let our first act every morning be to make the following resolve for the day: I shall not fear anyone on earth. I shall fear only God. I shall not bear ill will toward anyone. I shall not submit to injustice from anyone. I shall conquer untruth by truth. And in resisting untruth, I shall put up with all suffering. - Mahatma Gandhi

Strengthening Families Together

Helping Canadians Live with Mental Illness

Strengthening Families Together This 8-session national education program for family members and friends of individuals living with and recovering from serious mental illnesses aims to increase accessibility to Canadian-based information on the topics associated with living daily with a mental illness.

Strengthening Families Together is about more than education; it is about strengthening family members and friends of individuals with a serious mental illness by providing support, awareness, and tools.

discuss the daily challenges they face and learn how to connect with others through their local schizophrenia provincial society.

Awareness > Families get reliable and consistent information about mental illness, causes, treatment options, recovery, and available mental health services, in the hopes of diminishing the stigma attached to diagnosis.

The Program Outline

Session 1 > Introduction to Mental Illness & the Strengthening Families Program

Session 2 > Facts about Psychosis (Causes & treatments)

Session 3 > Coping as a Family

Session 4> Self Care

Session 5 > Communication

Session 6 > Living with Psychosis

Session 7 > Understanding the Mental Health system & Advocacy

Session 8 > Recovery with guest speaker

The Strengthening Families Group is being offered by the

Manitoba Schizophrenia Society in Winnipeg at 4 Fort Street.

This 8 week workshop will run each Wednesday evening
7:00pm to 9:00pm
Starting: Wednesday, March 18, 2009
Ending: Wednesday, May 20, 2009

For further information and registration please call: Viola at **786-1616**

More Education Needed on 'Youth's Greatest Disabler'

By ALLISON JONES - The Canadian Press

Nigel Bart first had an inkling that something was different about him when on a trip to B.C. after high school graduation, he tried to summon the wind. His family had entered a sailboat race, but there was no wind that day.

"An urge in me thought that maybe if I prayed hard enough I could somehow make the wind blow and make our sailboat win the race," he says. "So, I closed my eyes and I started gesturing with my hands, kind of like making the wind blow, like conducting an orchestra. That was the first clue."

Bart, now the head of Art Beat Studio in Winnipeg, which incorporates art with a mental health recovery program, didn't know anything about schizophrenia at the time. But looking back on events like this one about 15 years ago, he says there were subtle clues pointing to the onset of mental illness.

"Before a person has what we call a psychosis...people are going to have preliminary signs," says Chris Summerville, the CEO of the Schizophrenia Society of Canada.

Some of the signs include: change in behaviour, change in sleep patterns, irritability, avoiding social activities, becoming reclusive, difficulty with studies and a change in appearance or hygiene.

"When a person does get a diagnosis of psychosis and schizophrenia, people will often say, 'Well this is what I did see and I just thought it was adolescence and they were just going through a stressful time.'"

But the teen years are exactly when the symptoms of schizophrenia can start to show up.

"It has often been called youth's greatest disabler because the primary onset of schizophrenia, along with all other major mental illnesses, is during adolescence," Summerville adds.

He says parents and people who work with adolescents should look for a cluster of symptoms over a period of time — not just somebody having a bad weekend.

Tammy Lambert started experiencing symptoms of what would later be diagnosed as schizoaffective disorder, which has components of both schizophrenia and mood disorders, when she was 14.

During manic highs she would get a sense of "Heaven on Earth" and of prophecies. During periods of depression, a delusion of being under surveillance combines with the depression to make her feel like she's a bad person and people are conspiring to kill her.

"One time I had a friend over and we were watching TV and I got a message from the television," Lambert says, remembering one of her first episodes when she was about 15 years old.

"I said to him, 'Can you please get out. I don't want you here right now.' I thought that he was part of a conspiracy and the message on the television was telling me he was part of the conspiracy. I kicked him out and then I barricaded my doors."

Lambert calls the onset of her symptoms "a gradual process" that culminated in several sleepless nights in a row, a foggy feeling, distorted images in her mind and messages from the television and newspaper. That's when she sought help and eventually got her diagnosis, which she says was partly a relief.

"It made me feel good because I actually finally understood what was happening to my mind," she says. "But then it made me feel bad because nobody wants to accept the fact that they have a mental illness. It's very stigmatizing. Especially for somebody in high school."

For Bart, it was the time just after high school, when he started studying science at the University of Winnipeg that his symptoms really started to appear. "I knew I was different from most other people," he says.

He began to repress natural urges: hunger, thirst, urination and even sexual urges. He started looking for signs from God or signals in people's coughs or subtle gestures.

"It was like I was on automatic override," he says. "I wasn't making any deliberate conscious movement. I was acting basically all out of what I believed was some kind of spiritual intuition."

Bart would get on the bus in the morning and find himself still riding the bus late into the night after following signals all day.

However, he also felt relieved at hearing a diagnosis, finally "an answer to all of this madness," he says. After that came what he calls his "convalescence period," when he got much-needed support from treatment and his family. He got his degree in fine arts, which led him to Art Beat Studio.

Lambert is now working toward a bachelor of arts degree at the University of Manitoba and hopes to become an occupational therapist. She also does presentations now on her experiences.

"There really does have to be more education, more understanding of what mental illnesses are and what they entail," she says, "because there is still tons of discrimination."

Global Mental Health Discrimination Rife

Research from the Institute of Psychiatry at King's College in London, published by The Lancet, looks at the global pattern of experienced and anticipated discrimination against people with schizophrenia. In the 27 countries researched, negative experienced discrimination is reported by 95 per cent of the participants.

The experiences of discrimination are remarkably consistent across countries in the different areas of life such as making or keeping friends, finding a job and maintaining personal relationships. Researchers also found that even in the absence of experienced discrimination, such people actively anticipate they will be discriminated against in whatever they do.

Graham Thornicroft, Professor of Community Psychiatry at the King's, and lead researcher on the Lancet paper comments: *"Many people with schizophrenia experience stigma caused by other people's knowledge, attitudes and behaviour; this can lead to impoverishment, social marginalization and low quality of life. The aim of our study was to describe the nature, direction and severity of anticipated and experienced discrimination reported by people with schizophrenia and the fact that the findings are consistent across the 27 countries studied shows that the discrimination experienced or anticipated by people with mental illness is a global concern."*

Key findings

For the study published online, 732 participants were interviewed across 27 countries, all of whom had a diagnosis of schizophrenia. The 95 per cent who reported at least one negative experience of discrimination (they were asked 32 questions), on average reported discrimination in more than five areas of their everyday lives. For example, 47 per cent had experienced negative discrimination in making/keeping friends and 43 per cent had experienced negative discrimination from family members. Coupled with this:

- 29 per cent experienced negative discrimination in finding a job
- 29 per cent experienced negative discrimination in keeping a job
- 27 per cent experienced negative discrimination in intimate or sexual relationships
- 93 per cent of participants anticipated discrimination in at least one area of life; e.g. 64 per cent in applying for work/training/education, while 72 per cent felt the need to conceal their diagnosis.

Positive discrimination was rarely experienced (7.6 per cent of all responses), while experiences of positive discrimination are concentrated in a few key areas; e.g. 24 per cent felt treated more positively by family and 18 per cent felt they had experienced positive discrimination in getting welfare benefits or disability pension.

Of those who anticipated discrimination in work, 52 per cent had not experienced it. Of those who anticipated discrimination in intimate relationships, 56 per cent had not experienced it. Statistical analysis demonstrated that anticipated discrimination was the strongest predictor of experienced discrimination, with experienced discrimination increasing by 1.17 units on average as anticipated discrimination increased by one unit.

Commenting on what the research has revealed, Professor Thornicroft continued: *"The rates of both anticipated and experienced discrimination are consistently high across countries among people with mental illness. Measures such as disability discrimination laws might not be effective without interventions to improve self-esteem of people with mental illness."*

From: King's College London, England 21 Jan 2009, PR 14/09

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Manitoba Schizophrenia Society, Inc. is a consumer focused, family sensitive mental health self help organization whose mission is to improve the quality of life for those affected by schizophrenia/psychosis and co-occurring disorders, through education, peer support and advocacy.

Reasons for Hope is the official newsletter of the Society. It is published quarterly. Submissions are invited. **Opinions set forth in this newsletter are not necessarily those of the Society or its members.** Reprinting of articles is permitted with the proviso the Society is given appropriate credit.

Editor: Chris Summerville, *Executive Director*

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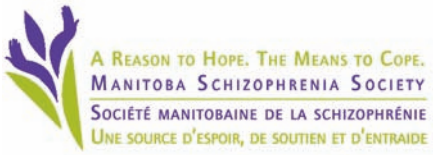

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MSS is a registered non-profit organization. Charitable donation #88938 3998 RR0001

❒ Single, $15 ❒ Family, $25 ❒ Corporate, $50

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