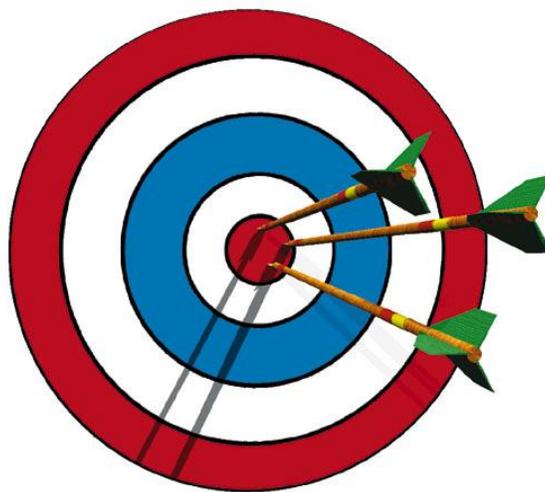


**A TIME FOR ACTION:  
TACKLING STIGMA AND DISCRIMINATION**



**Report to the Mental Health Commission of  
Canada**

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## Table of Contents

EXECUTIVE SUMMARY .....	3
Purpose of the Report.....	4
A TIME FOR ACTION .....	8
Review of the Literature .....	8
Canadian Online Survey Results.....	19
Key Informant Interviews .....	29
Recommendations for the MHCC: .....	36
APPENDICES.....	40
Appendix A – International Stigma Programs Reviewed .....	40
Appendix B – Literature Review Reference.....	40
Appendix C - Canadian Activities – Listed Geographically.....	40
Appendix D - Key Informant Interview List .....	40



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*Neasa Martin & Valerie Johnston*



## EXECUTIVE SUMMARY

### Purpose of the Report

The Mental Health Commission of Canada (the Commission) has identified the elimination of stigma and the reduction of discrimination as one of the top three priority areas to be addressed as part of its federal framework for mental health. The recent work of the Senate Committee has elevated interest in mental health and mental illness to unprecedented heights. Consequently, stakeholders have high expectations for action on the part of the Commission. This report is intended to orient the MHCC Board of Directors, inform its deliberations and make recommendations for action to address stigma and discrimination, based on a broad review process.

For people living with mental health and addiction problems, and for their families, the challenges associated with their illness have long been exacerbated by the experience of stigma. Despite significant advances in the treatment and management of serious mental illness over the past two decades, stigma and the prejudice and discrimination which accompany it, have remained real and present realities. Stigma and discrimination are experienced in multiple domains: at home, within friendships, in intimate relationships, at work, in the community, in the healthcare system and in the media. They are also felt in the low priority mental illness and addictions are ascribed by policy makers, planners, researchers and those who fund mental health and addictions research and treatment delivery.

In recognition of the low priority ascribed to people with mental health and addictions issues many groups and organizations, both in Canada and around the world, have developed stigma reduction programs. For the most part, Canadian initiatives have developed without a shared agreement of what stigma is and how it should be tackled, in relative isolation and with little coordination amongst them. There has been limited funding to support these programs, insufficient research available to inform their development and their outcomes have been inadequately evaluated. In contrast an increasing number of international jurisdictions have established mental health strategies and Mental Health Commissions with robust national anti-stigma/discrimination campaigns from which Canada can learn. Although experts do not all agree on strategy, there is emerging research that provides valuable insights into what



works and what doesn't.

The high expectations of Canadians for urgent action create both opportunities and challenges for the MHCC. The Commission's greatest strength will be its ability to serve as a catalyst for change by mobilizing key stakeholders to coordinated action. Given the high level of interest already expressed, the Commission can harness already engaged groups. It must also reach out to important under-represented communities such as youth, the homeless, immigrant/refugee, and ethno-racial communities etc. to ensure their needs are well understood and included as priorities for the Commission and inform the development of a comprehensive, stigma/discrimination reduction strategy.

There is a strong desire to see the MHCC act in quick, bold and decisive ways to address what is seen as the most important impediment to both accessing treatment and achieving recovery. However, it is cautioned by leaders in the field to take the time to plan and build a long-term strategy informed by its broad stakeholder groups. An effective National strategy will require a multi-pronged approach targeted at specific groups as well as strategies to advance the development of integrated, responsive and recovery-oriented policies and services. The Commission does not need to re-invent the wheel but can draw on emerging expertise to learn what works, what are promising approaches and more importantly what will not achieve the desired outcomes. It can also play a leading role in building this international knowledge-base by being innovative in its approach and by creating a culture that supports and promotes research and evaluation so that we can continue to refine our strategies to best effect.

There are many areas of strong agreement amongst Canadians, the emerging research and those experts consulted through this review. Agreement includes the importance of engaging consumer/ service users at all levels of decision-making and service delivery based on their unique understanding and direct experience of stigma and discrimination. Their high personal stake in achieving positive outcomes will serve to orient, motivate and guide the Commission. There is also agreement that change is best accomplished at the local community level. It is agreed that the Commission will achieve its greatest impact by partnering with groups and organizations with an interest in change. That the approach and messaging needs to be targeted and



shaped by the unique cultural needs of the target groups and is best delivered by members of the community. This was seen as of particular importance in addressing the needs of Aboriginal communities who have unique histories, community and cultural belief and ways of understanding the continuum of health wellness and disease. Although this is no less true for other communities (ethno-racial, gay and lesbian, immigrant/refugee etc.) who's opinions may not have been captured through the MHCC survey.

There is also universal agreement that it is through repeated, direct contact with people with mental illness and addictions, who disconfirm widely held prejudice, that attitudes and behaviours are substantively changed. There is also wide-spread agreement that targeting behaviours, not just attitudes and focusing on rights and entitlements is essential for meaningful improvement in the quality of life of people with mental illness and addictions. That targeting specific groups for anti-stigma/discrimination messaging is essential particularly with those groups with the greatest power and influence to either advance recovery or impede its progress. These include health/mental health service providers, policy planners and funders, employers and human resource personnel, emergency staff, policy planners and funders and social service personnel. Building the capacity for consumers/service users to be fully engaged in planning and decision-making will be an essential first step if they are to serve this important role as agents of change.

At the same time there is considerable variance between what many Canadians want from the MHCC and what the emerging research suggests and expert advisors recommend the Commission do. There is currently no shared agreement in Canada on which approaches are most effective for reducing stigma and discrimination, who should be the target of focus for change or coordination of efforts currently underway to address stigma. This lack of shared understanding and uncoordinated efforts hampers Canada's ability to gain maximum traction. Although the concept of wellness and recovery is broadly accepted there is widely varying ideas of what this means at an individual, service and systems level. By providing a clear vision on how to address stigma and discrimination and creating a shared understanding and agreement to act the Commission will be able to effectively mobilize its large and varied community of stakeholders to deliver coordinated and targeted anti-stigma activities.



## A Time For Action: Tackling Stigma and Discrimination - MHCC

Finally, the tension between the desire for immediate and bold action from the Commission and the need for thoughtful planning and engagement of key stakeholder groups needs to be reconciled. By focusing on achieving highly visible 'quick wins' that reflect its core values and mandate the Commission can buy time to thoughtfully engage consumers and plan its long-term course. It will also be important to identify ways to communicate with, maintain the interest of, and engage the enthusiastic throng of Canadians willing to support the MHCC efforts. The recommendations made in this report attempt to balance this evident tension.



## A TIME FOR ACTION

### Introduction

This report is intended to inform the deliberations of the MHCC Board and to recommend actions that it can take to address stigma and discrimination. The Consultants arrived at these recommendations through the following process:

- ④ *Review of the literature* designed to identify evidence-based research and promising practices
- ④ *Online survey* to identify and assess current anti-stigma initiatives across Canada
- ④ *Interviews* with Canadian and international experts to identify state-of-the-art anti-stigma initiatives and provide advice to the Commission
- ④ *Consultation* with international mental health leaders through the International Initiative in Mental Health Leadership to test the Consultants' preliminary recommendations

### Review of the Literature

The Consultants conducted a high-level review of stigma-related literature. Sources ranged from peer-reviewed journal articles, through "grey" literature provided by key informants, to pamphlets describing stigma reduction programs<sup>i</sup>. More than 50 documents were analyzed for answers to the following five questions:

- *What is stigma?*
- *Why does it exist?*
- *What is its impact?*
- *What is being done to address it?*
- *Which approaches are most effective?*

### What is Stigma?

*"Stigma is typically a social process, experienced or anticipated, characterized by exclusion, rejection, blame or devaluation that results from experience or reasonable anticipation of an adverse social judgment about a person or group."<sup>iii</sup>*

That definition, developed by researchers to inform an international workshop on



health-related stigma and discrimination in 2004, reinforces what people with mental illness have long known about stigma.

Consumers experience stigma as a mark of shame, disgrace or disapproval that sets its bearer apart from others.<sup>iii</sup> It makes them a target of scorn, censure, ridicule, or condemnation<sup>iv</sup>, constrains their opportunities and limits their options. The experience of stigma exerts a powerful influence on a person's identity and leads to the assumption of social roles that, over time, become central to the way in which the individual is viewed and, ultimately, views themselves.<sup>v</sup> Any condition that deviates from what a given society considers 'normal', including mental illness, may become a target of social stigma. Consequently, stigmatized conditions vary across cultures and over time.<sup>vi</sup> In this culture, the stigma of mental illness has endured for centuries.<sup>vii</sup>

### **Three types of stigma have been identified:**

*"Health-Related Stigma"*<sup>viii</sup> can lead to exclusion, rejection, blame or devaluation of the individual affected by stigmatized conditions at a time when they are most in need of inclusion, acceptance and compassion.<sup>ix</sup> Negative social judgments about the conditions themselves can have significant implications for social and health policy. In addition to mental illness, contemporary stigmatized conditions include sexual dysfunction, HIV/AIDS, leprosy and epilepsy.<sup>x</sup>

*"Self Stigma"* describes the process by which individuals internalize negative attitudes about their own condition<sup>xi</sup> - concluding that they are unworthy of anything other than poor treatment. They come to expect rejection, and they receive it - an experience which then reinforces the original expectation. In response, they develop coping strategies which often include secrecy and withdrawal.<sup>xii</sup>

*"Courtesy Stigma"* describes the stigma-by-association experienced by those who are closely associated with stigmatized people.<sup>xiii</sup> Families, friends and mental health professionals - all of whom may experience courtesy stigma - may be seen by the rest of society, as "normal yet different", by virtue of their affiliation. To protect themselves against the negative social judgment implicit in that label, close associates - including mental health professionals - may distance themselves from the stigmatized person, thus reinforcing the "us/them" dichotomy of which people with mental illness are so acutely aware.<sup>xiv</sup> Some theorists suggest that chronic under-funding of psychiatric



services and research is, at least in part, a manifestation of courtesy stigma on the part of policy makers. <sup>xv</sup>

### ***Why does stigma exist?***

Stigma can be seen as a constellation of three related problems:

- a lack of knowledge (i.e. *ignorance*)
- negative attitudes (i.e. *prejudice*)
- excluding or avoiding behaviours (i.e. *discrimination*)<sup>xvi</sup>

Theories abound about why stigma exists. Most explanations involve multiple factors in complex interaction. There is general agreement, however, that stigma is born of ignorance, fear and mistrust of differences – all reinforced by negative social judgments about the nature of the difference and the person who manifests it.<sup>xvii</sup>

With respect to mental illness, public ignorance and fear remain widespread. The 2007 report *Mental Health Literacy in Canada* concluded that laypeople still have a poor understanding of mental illness and that they are afraid of those they perceive as mentally ill. Despite the numerous anti-stigma campaigns conducted over the last thirty years, the report further suggests that the public is now *more* inclined than they were a few decades ago to perceive people with mental illness as dangerous.<sup>xviii</sup>

That mistaken belief appears to be the result of repeated exposure to *misinformation* (most of which is provided by the mass media) of a type that reinforces negative perceptions and generates fears of unpredictability and violence.<sup>xix</sup> Children's television programming is a particularly troubling source of misinformation – with an overwhelming number of denigrating references to the mentally ill. Given that, it is not surprising that young people today display *less* favourable attitudes than adults toward mental illness and greater reluctance to seek help for mental health problems. <sup>xx</sup>

### ***What is its impact?***

The impact of stigma is both far-reaching and profound. It affects family, friends and the professionals who serve people with mental illness, as well as the individuals themselves. No aspect of a stigmatized person's life remains untouched.



Two words echo throughout the literature on the impact of stigma – ‘disrespect’ and ‘barrier’. Consumers experience stigma as a mark of disrespect – a comment on their relative value to society and the disdain (and sometimes outright hostility) with which they are viewed. The language used to describe people with mental illness betrays that judgment, with a predominance of strongly negative terms – ‘nuts’, ‘psycho’, ‘loony’, ‘freak’<sup>xxi</sup> - the equivalent of which would be unacceptable if used to describe any other disenfranchised population. For many people with mental illness, daily exposure to denigration and disrespect is the norm.

The effectiveness of stigma as a barrier cannot be overstated. It limits opportunities and restricts options. Access to housing, employment, education and health care may be severely constrained. Relationships may be diminished and physical health compromised. Quality of life deteriorates. People who identify with their diagnosis experience poor self esteem, loneliness and despair – sometimes resorting to suicide to alleviate the pain.<sup>xxii</sup> Not surprisingly, many people choose not to “join” this stigmatized club and avoid seeking help, even when it would be in their best interest.<sup>xxiii</sup> Others refuse to comply with the recommended treatment for the same reason.<sup>xxiv</sup>

Stigma can also have a profound impact on social policy. When faced with competing demands for finite public resources, legislators often choose to invest in other, more “worthy” causes, rather than support a system designed to serve those with little political influence, for whom the public has little sympathy and who are believed to be beyond hope.<sup>xxv</sup> Punitive legislation and regressive policies designed to exclude, reject and control the mentally ill often accompany this fiscal constraint.<sup>xxvi</sup>

Most importantly, from the perspective of many consumers, stigma results in a denial of the rights and responsibilities that accompany full citizenship. They urge that we call it what it is – *discrimination*<sup>xxvii</sup> For some consumers the experience of discrimination generates righteous indignation and provides them with the energy they need to fight for what is rightfully theirs.<sup>xxviii</sup> For others, stigma means only despair and pain.<sup>xxix</sup> Consumers seek to alter that reality, and offer the following plea:



*"To the people of Canada, I say welcome us into society as full partners. We are not to be feared or pitied. Remember, we are your mothers and fathers, sisters and brothers, your friends, co-workers and children. Join hands with us and travel together with us on our road to recovery."*

*Roy Muise — 9 May 2005 – Halifax <sup>1</sup>*

The World Health Organization supports their request, noting that:

*"Governments have been remiss, as has been the public health community. By accident or by design, we are all responsible for this situation. As the world's leading public health agency, WHO has one, and only one option to ensure that ours will be the last generation that allows shame and stigma to rule over science and reason."*

*Dr. Gro Harlem Brundtland, Dir. Gen., WHO, 2001<sup>2</sup>*

### **What is Being Done to Address Stigma?**

The recent proliferation of anti-stigma programs, both in Canada and around the world, is reflective of new levels of concern about the impact of stigma on the lives of people with mental illness.

In addition to the Canadian initiatives described in Appendix C, the Consultants reviewed documentation related to 15 programs from other jurisdictions<sup>3</sup>, as well as an international effort designed to focus attention on stigma in 155 countries simultaneously:

1. Breaking the Silence (U.S.A.)<sup>xxx</sup>
2. Change Your Mind About Mental Health (U.S.A.)<sup>xxxi</sup>
3. Entertainment Industries Council (U.S.A.)<sup>xxxii</sup>
4. In Our Own Voice (U.S.A.)<sup>xxxiii</sup>
5. Nothing to Hide, (U.S.A.)<sup>xxxiv</sup>
6. Active Minds on Campus (U.S.A.)<sup>xxxv</sup>
7. The Kids on the Block (U.S.A.)<sup>xxxvi</sup>

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1 Out of the Shadows at Last. [www.parl.gc.ca/39/1/parlbus/commbus/senate/com-e/soci-e/rep-e/rep02may06-e.htm#\\_ftn2#\\_ftn2](http://www.parl.gc.ca/39/1/parlbus/commbus/senate/com-e/soci-e/rep-e/rep02may06-e.htm#_ftn2#_ftn2)

2 Mental Health: A Priority for World Action: [www.who.int/director-general/speeches/2001/english/20011025\\_copingwithstressbrussels.en.html](http://www.who.int/director-general/speeches/2001/english/20011025_copingwithstressbrussels.en.html)

3 See Appendix A for an analysis of the international programs reviewed



8. Stigma Watch (Australia)<sup>xxxvii</sup>
9. The Carter Centre (U.S.A.)<sup>xxxviii</sup>
10. Like Minds, Like Mine (New Zealand)<sup>xxxix</sup>
11. Beyond Blue (Australia)<sup>xl</sup>
12. Mind (England)<sup>xli</sup>
13. See Me (Scotland)<sup>xlii</sup>
14. SAMHSA (U.S.A.)<sup>xliii</sup>
15. Mental Health Law Centre (Australia)<sup>xliv</sup>
16. Stop Exclusion, Dare to Care<sup>xlv</sup>

The variability of those programs speaks to the range of approaches currently employed. Around the world, anti-stigma efforts focus on a variety of objectives, some of which are defined as follows:<sup>4</sup>

- To provide education, challenge stereotypes and dispel myths of mental illness (1, 5, 7, 8, 9, 11,)
- To help change public perceptions and attitudes about mental illness (2, 13,14)
- To increase access to health care for individuals experiencing mental illness (2)
- To decrease discrimination and promote inclusion (2, 10, 12)
- To promote accurate and positive media portrayals of people with mental illness (3)
- To encourage self-confidence and self esteem in people with mental illness (4, 12)
- To focus on recovery and the message of hope (2, 4, 14)
- To provide a forum for families to speak candidly about their experience of stigma (5)
- To encourage students to seek help (6)
- To encourage legislative change (10, 12, 13)

Target audiences include elementary (1, 7), secondary (2) and post secondary school students (6), the entertainment industry (3), the media (8, 9) the general public (5, 8, 13), health care professionals (4), and legislators (9, 10, 12, 15) among others.

Such varied objectives demand multi-pronged strategies. The programs reviewed

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<sup>4</sup> The numbers following each characteristic indicate the programs to which they apply



utilize an array of approaches - ranging from games (1), puppet shows (7) and photographic exhibits (5), through personal testimony (4, 5) and speakers' bureaux (4, 13) to conferences (3, 12), media watches (8, 13), journalism fellowships (9), public service announcements (2, 10, 13) and workplace programs (13) - each designed to appeal to a particular audience or to communicate a particular message.

Some of the jurisdictions studied adopt a comprehensive approach, with multiple activities comprising an integrated, multi-pronged strategy. *Like Minds, Like Mine*, a multi-year project delivered by the New Zealand Ministry of Health, operates from the premise that *discrimination*, not *stigma*, is the critical issue. In keeping with that conviction, *Like Minds* advocates for a reduction in compulsory treatment and the reduced use of seclusion in the treatment of mental illness; provides a disability perspective on policy advice to Cabinet, and educates people with mental illness about their rights under the *Human Rights Act*, in addition to many of the approaches identified above.

Australia has also developed a comprehensive strategy which involves multiple governmental and non-governmental partners, and includes a media- focused public education campaign on the signs and symptoms of the most common mental illnesses (beyondblue), anti-stigma initiatives and monitoring (Sane Australia), workplace education, media watch (Mindframe Australia), and legal advocacy (Mental Health Law Centre).

In the United States, the Federal government's Substance Abuse and Mental Health Services Administration (SAMHSA) has set its mission on building resilience and facilitating recovery for people with, or at risk of, mental or substance use disorders. SAMHSA addresses stigma and discrimination through multiple tracks including consumer-focused grants, multi-media campaigns, programs, knowledge exchange, monitoring, research and training.

England's National Lottery recently committed £18 million for a comprehensive, four year multi-sector, anti-discrimination initiative which includes: a national media-based anti-stigma campaign; broad local community involvement to encourage consumer fitness, empowerment and engagement; training and education, targeting leaders and professionals to reduce discriminatory behaviours; and legal programs to challenge



discriminatory policy and legislation (Mind). Through 'see me' Scotland has developed a multi-sector alliance to challenge stigma and discrimination through a national media and publicity campaign, media watch, speakers bureau, employment and workplace programs and policy advocacy.

The same broad range of objectives, target audiences and approaches was evident in the selection of strategies employed by the 155 countries which participated in the World Health Organization's Global Advocacy Campaign in 2001. "*Stop Exclusion Dare to Care*" was the banner under which countries from Australia to Zimbabwe sought to reduce stigma. Activities around the world included the following:

- An exhibition of children's drawings and paintings during a public event in a major shopping mall (Bahrain)
- A 10 kilometre walk for mental health (Botswana)
- A rally with speeches by officials, religious leaders, traditional healers and teachers (Chad)
- Free medical consultations provided for one week (Guinea)
- A performance of a specially commissioned play portraying the journey through a person's mind (India)
- Information stands throughout the city of Barcelona (Spain)

Some events targeted youth:

- Regional workshops for high school students (Italy)
- Football matches with teams wearing WHO uniforms (Somalia)

Others sought to influence decision makers, health care providers or other stakeholders:

- A meeting between parliamentarians, members of government, NGOs and religious leaders to sensitize law-makers about mental health issues (Angola)
- International meeting of associations to overcome social exclusion and guarantee the right to care (Italy)
- Special parliamentary sessions on mental health and substance abuse (Poland, Slovakia, Sweden and Thailand)
- Training conferences for psychiatrists (Australia)



Together, these programs helped to raise public awareness of an issue too long kept in the dark. The WHO concluded that:

*"World Health Day harnessed international momentum and generated a multitude of activities for influencing public perception, strengthening professional networks, empowering consumer associations and raising awareness among decision-makers to result in improved services, legislation and policy."*

Dr. Derek Yach, Executive Director  
No communicable Diseases and Mental Health WHO, 2001<sup>5</sup>

Clearly, however, there is still much to be done.

### ***Which Approaches are Identified as the Most Effective?***

Concern about the impact of stigma on the lives of people with mental illness is a relatively recent phenomenon. Given that, it is not surprising that our knowledge and understanding of effective strategies to combat stigma is not yet fully developed. The absence of standardized tools which are validated across cultures, inconsistent research approaches, methodological flaws, and gaps in data, all contribute to a situation in which the current level of anti-stigma activity outstrips the research base necessary to fully inform it.<sup>xlvi</sup>

In general, however, we know that there is no quick fix and no single answer. Instead, many authors suggest a three-pronged approach:<sup>xlvii</sup>

- Education (to dispel commonly held myths about mental illness)
- Protest (to suppress discriminatory attitudes and challenge commonly held stigmatizing images)
- Contact (to put a human face on mental illness – whether that of celebrities or of the not-so-famous)

None of those three approaches is completely successful on its own, however studies have repeatedly found that *contact* is the most effective single strategy in countering stigma and discrimination.<sup>xlviii</sup> Direct person-to-person experience with someone who

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<sup>5</sup> Results of a Global Advocacy Campaign. [www.who.int/mental\\_health/media/en/257.pdf](http://www.who.int/mental_health/media/en/257.pdf)



has a mental illness can create long-term attitudinal change and affect behaviour<sup>xlix</sup> however, some conditions do apply. For contact to be most effective, a number of criteria must be met. Such factors include:

- Interactions in which all individuals have equal status
- Opportunities for people to get to know each other (i.e. situations that allow for 'acquaintance potential')
- Exchange of information that disconfirms negative stereotypes
- Pursuit of mutual goals
- Situations that require active co-operation<sup>l</sup>

Authors urge caution in the use of *protest* strategies, suggesting that, although they may help to reduce self-stigma, they don't appear to have lasting impact on public attitudes and behaviour and may, in fact, have a 'rebound effect' further embedding stigmatizing beliefs or forcing them 'underground'.<sup>li</sup>

Perhaps surprisingly, *education* does not appear to have a significant effect if provided in isolation from the first two approaches. Although education may result in some mild improvement in stigmatizing attitudes, there is little evidence that it translates into long-term behavioural change.<sup>lii</sup> The incidence of stigma among mental health professionals (who, arguably, have more education with respect to mental illness than anyone else) may be seen as evidence of the tenuous link between information and behavioural change.<sup>liii</sup>

Given the inadequacy of any single approach, all of the authors studied recommend a multi-faceted strategy. The following is a consolidated list of principles, drawn from the literature<sup>liv</sup>, to inform that comprehensive approach:

#### *Participation and Leadership*

- Consumer/survivor involvement and leadership is critical to the success of any anti-stigma initiative
- A dedicated "champion" at a senior level of government can help to ensure success
- Active participants must be asked to make a long-term commitment to the project



*Program Goals and Objectives:*

- Program goals should be established in consultation with mental health consumers and their families
- The campaign's goals and objectives must be clearly articulated

*Selection of Change Targets and Key Messages:*

- Programs should be directed at carefully defined target groups, rather than at "the general public"
- Appropriate messages must be developed for each target audience
- Energy and resources should be focused on areas in which success is most likely, and on people who are interested in change
- To encourage ongoing participation, programs should be undertaken first in areas in which "early wins" can be achieved to build program success and momentum
- The more targeted the intervention, the greater the likelihood of success.

*Sustainability:*

- Campaigns that aim to change attitudes and behaviour must be sustained over time
- Anti-stigma initiatives must be adequately funded
- Evaluation protocols must be "built in" to each campaign
- Information about both the project itself and its outcomes should be broadly disseminated.

*Legislative and policy change:*

- Anti-stigma campaigns should be coupled with efforts to enact legislation and develop social policy to establish and enforce the human rights of people with mental illness.

Those principles, and the multi-pronged approach proposed by the Consultants, are similar to those employed by the gay and lesbian community to destigmatize homosexuality in the latter part of the twentieth century. A focus on rights protection, equal access to housing and employment, the avoidance of public labels that imply derision, and the mobilization of the gay community's economic and political clout shifted the discourse from deviance and stigma to human rights and discrimination.



That same strategy, if implemented consistently, could assist in breaking down public distinctions between “them” (people with mental illness) and “us” (those who haven’t yet been diagnosed) and contribute significantly to eradicating stigma.

## Canadian Online Survey Results

Over a six week period 1,325 Canadians participated in an online survey<sup>6</sup> focused on stigma and discrimination (1,298 English; 27 French<sup>7</sup>). Respondents came from all regions of Canada and reflect a diverse group of stakeholder interests. Fifty-six percent defined themselves as health care professionals, 30% as consumers, 26% as family, 9% researchers and 8% policy planners. Interestingly, over 440 participants reported having multiple roles, including the combined perspectives of consumer/family/ policy/researcher and health care providers. The level of public response significantly exceeded initial expectations and reflects the high level of interest and investment on the part of Canadians in shaping the activities of the MHCC.

Participants were asked to:

- ① Identify current Canadian anti-stigma activities
- ① Provide input into which activities they felt represented the very best campaigns and explain why
- ① Describe how they measure the success of their initiatives,
- ① Identify the elements that they believe contribute to making an effective anti-stigma campaign
- ① Identify the preferred targets of those initiatives
- ① Provide their best advice to the Commission as it moves forward.

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6 The survey was conducted between June 15th and Aug. 4th 2007. There were 457 completed surveys. Complete survey findings can be found at: [http://www.surveymonkey.com/sr.aspx?sm=STZ8eiwUgCsdAgePrTKTXA8CBk\\_2fZ6dnI3xv6XIYb7s\\_3d](http://www.surveymonkey.com/sr.aspx?sm=STZ8eiwUgCsdAgePrTKTXA8CBk_2fZ6dnI3xv6XIYb7s_3d)

7 Although a similar dissemination strategy was used to garner input from the francophone community the much lower response rate is worth noting. The short timeline for participation and the restrictions imposed by using an on-line survey are important limitations. Although the number of French responses is considerably lower the themes, concerns and emerging priorities were remarkably similar to the English responses.



## Emerging Survey Themes

### ***Expectations are high – the desire for action is urgent***

Survey respondents see stigma as a very real, acute and enormous problem. Consequently, their expectations of the MHCC are extremely high, as are their hopes that it will act immediately and decisively to address stigma. There is a strong desire for the Commission to take a leadership role and to move quickly, act boldly and not become mired in extensive consultations and planning activities. At the same time there is also an understanding that a long-term strategy will be required, that changing public attitudes is a challenging goal which will take years to accomplish, and that a multi-faceted, sustained and repeated approach will be necessary.

### ***Partner with the Community***

It was repeatedly noted that there are significant activities already underway in Canada and community leaders who are well ahead of the Commission in addressing this issue. Respondents want to partner with the Commission, to share their expertise and to build their capacity to develop and deliver programs within their own communities. In fact, over 350 respondents offered ongoing support and assistance to the Commission in doing its work. Building the capacity for stakeholders to act, enhancing their funding opportunities, and engaging political partners at the federal and provincial level to support provincial and regional activities were all seen as early strategic priorities for the Commission.

### ***Consumers/service users MUST play a central role***

Respondents agree that including consumers in both the design and delivery of programs is essential to the success of any anti-stigma campaign. They believe that, because stigma and discrimination is most directly felt by consumers, they have unique insights into which priorities need to be addressed, a high stake in the outcome and a central role in program delivery. Therefore, consumers must be engaged at every level of planning. Families were also identified as important stakeholders in program planning. However, they were also seen as an important audience for anti-stigma efforts – one that requires a targeted approach to help align their beliefs and actions and to promote messages of hope and recovery.



### ***Personal contact is the method***

Direct peer-based contact and personal stories, targeted at changing the heart - not just the mind of the listeners, was consistently identified as the most persuasive strategy for addressing stigma. The need to 'normalize' the experience of mental illness and addictions, and move people from a sense of 'them and us' to 'we' was repeatedly stressed. Portraying 'normal' people from varied economic, social and ethno-racial, backgrounds and providing a forum for them to share their lived experience was believed to help reflect our shared 'human-ness'.

Personal stories which realistically portray the challenges, obstacles, and losses people encounter, their journey to finding help, the factors that made a difference in their lives and, most importantly, which convey a message of hope and recovery were thought to have the greatest, most sustained impact on attitude. Challenging popular myths surrounding mental illness through peer contact with those who defy commonly held beliefs of difference, dangerousness, incompetence and impulsivity was believed to have the most lasting effect. An equal number of respondents suggested that using 'famous celebrities' in campaigns was an effective anti-stigma approach. Many encouraged the Commission to experiment with a variety of approaches and to evaluate their impact carefully in order to build a better understanding of what works best.

### ***Wellness and recovery is the goal***

A focus on recovery and not illness was identified as an important priority for moving public perception away from what is 'broken' and towards 'what helps us heal'. At the end of the day it is striving to achieve and/or restore a high quality of life, including employment (whether paid or volunteer), friendships and supportive family, personal meaning, community involvement, safety, belonging and a sense of physical and mental health and well being, that unifies consumers, families/caregivers and health care providers. There is also a desire to see the Commission promote a broader understanding of mental health promotion, how it is nurtured, and that the requisite determinants of health are in place to support and sustain good mental health at the individual, family and community level.

### ***Move from a focus on stigma to addressing discrimination***

Many respondents felt that 'stigma' was a vague and poorly understood term of limited



utility, particularly with a general audience. Similarly, anti-stigma initiatives were seen to address negative attitudes, while dealing with systemic policy barriers and acts of discrimination was thought to address the behaviours which limit opportunity. Respondents suggested that changing attitudes was of little importance in supporting recovery, improving the quality of life or social acceptance of people with mental illness and addictions. They urged that the MHCC to shift away from stigma reduction and address, with legal resources and recourse, the discrimination that impedes full community participation and recovery. Many respondents felt inclusion of a human rights focus in the Commission's work would be a stronger, bolder message and more likely to yield greater benefits, improved quality of life and more measurable results.

### ***Activities are already underway in Canada***

Survey participants were asked to identify existing anti-stigma activities, More than 100 programs were identified across the country although no doubt there are countless more. Appendix C includes a complete geographic listing of identified programs. The diverse array of approaches currently being delivered includes the following:

- community information forums
- film festivals
- theatre programs
- consumer-led initiatives
- creative art programs
- school-based educational programs
- multi-media campaigns
- information websites
- self-evaluation tools
- discussion boards
- brochures
- fund raising walks
- family education programs
- advocacy training
- speakers bureaus
- media watches
- recognition awards
- annual awareness activities

Survey participants were also asked to define the most important elements of a successful strategy, and to describe how their anti-stigma initiatives are being evaluated. The approaches that are felt to have the greatest promise share the following elements:

- have clear, consistent simple message
- are sustained over time
- focus on personal stories which are authentic in tone and delivery



- are geared to challenging myths and providing factual information
- are delivered locally
- are designed to:
  - normalize mental illness,
  - stress a shared humanity,
  - invoke empathy,
  - provide opportunities for personal contact and discussion

Programs using the arts, i.e. theatre, documentaries, comedy, films etc. were also frequently mentioned as positive elements. Peer support programs were identified as a valuable vehicle for empowering consumers and neutralizing the harmful effects of self-stigma. Generally, there is agreement that there is 'no quick fix' for the problem of stigma, and no single strategy that will yield results. A recurring theme is the need to take a different approach to messaging – one which reflects an attitude of acceptance, a shared humanity and a lighter, more creative style.

### ***Education is highly valued – but may not be not the right tool***

There is evident tension with respect to the content of the message people wish to communicate<sup>8</sup>. For many respondents the desired message should focus on hope, recovery and success, and de-emphasize diagnosis and the elements of illness. There is a passionate subgroup of survey respondents who are committed to the value of education and enhancing mental health literacy about the signs, symptoms and aetiology of mental illness, as an essential element of stigma reduction. Many felt that teaching audiences about mental health problems as physical illnesses, like any other medical condition requiring medical treatment, should be the primary message for reducing stigma. However this view does not align with expert opinion on the most effective means of reducing stigma. In the absence of a robust research-base Canadians will remain committed to delivering programs which are instinctual rather than empirically based. Further research is required to ensure that programs are closely aligned to desired outcomes.

Enhancing mental health literacy is seen to have an important role in a national mental health strategy. However, based on this review of the research and consultations with

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<sup>8</sup> It is unclear whether this split in opinion reflects the differing perspectives of consumers, families and health care providers although this analysis of the data would be of interest.



expert advisors there is limited evidence to support the efficacy of this approach in reducing stigma. Early research suggests that, without personal contact, education may actually *entrench* negative attitudes and stereotypes particularly in relationship to psychotic illnesses. Many respondents felt that a combination of first person narrative and provision of factual information, delivered in partnership between consumers, families and health professionals, is the most effective strategy.

### ***There is no shared understanding of what an anti-stigma initiative is***

The survey revealed that there is currently no shared understanding within Canada about what constitutes an anti-stigma initiative, or about the activities that will result in a reduction of discrimination or removal of the barriers which impede full community participation. Many respondents believe that *any* activity designed to raise awareness of mental illness or addictions will have a stigma-reducing effect and, consequently, refer to everything they do as “an anti-stigma initiative”.

People noted that many existing anti-stigma initiatives are poorly funded, short-lived and based on an intuitive sense of what will work, rather than on any empirical evidence. A lack of research knowledge and skill, and financial and human resource limitations were identified as barriers to properly assessing the efficacy of these efforts. The limited funding available for these programs was seen by many as a further expression of stigma, reflecting the low priority it has received from funders, corporate partners and policy makers.

### ***Targeted messaging is important***

There is broad agreement that targeting programs to address specific audiences, and delivering programs locally, significantly improves information uptake. The need to segment and target programs at particular populations, with specific messaging and clear outcome goals was clearly identified. When asked to set priorities respondents identified the following audiences as extremely important:

Public	81%	Teachers	74%
Employers	80%	Health professionals	72%
Police/Corrections	79%	Families	66%

### ***Multiple target groups identified***

The sheer number of target groups identified reflects how widespread, pernicious and systemic Canadians feel stigma and discrimination is. Many felt that addressing



specific groups, using peers from within the community and delivering a targeted message will have the greatest impact for change. What is also clear is that Canadians are anxious for the Commission to initiate programs quickly to address each of these unique groups. Targeting health care professionals, including mental health professionals, was repeatedly identified as a high priority. Many felt that the negative attitudes and low expectations of some service providers was an expression of stigma, and that it contributes to their clients' reduced self-esteem, reinforces their self-stigma and presents a serious impediment to recovery.

### ***Focus on Youth***

Young people were the most frequently mentioned target population for anti-stigma activity. Many respondents believed that programs which start in primary school and, focus on mental health promotion, expose students to people with mental illness before negative attitudes are entrenched, and promote empathy and tolerance, may yield greater benefits than efforts that attempt to shift already strongly held beliefs in the population as a whole. Teens' poor knowledge and negative attitudes about mental illness, their increased vulnerability for mental health problems and their low rate of help-seeking behaviour make them an important target for intervention. Many felt that starting much earlier (i.e. in primary school) to include mental health and acceptance of differences as part of the curriculum would help to shape more tolerant behaviours overall.

### ***Use a segmented approach***

Workplace education was felt to be crucial, given the high levels of unemployment among consumers and the preponderance of long term disability claims resulting from mental illness. Other groups requiring a targeted approach included the following:

- people with mental illness (to address self-stigma)
- social service professionals (such as welfare and child protection workers)
- faith leaders
- community leaders (such as service clubs)
- the insurance industry
- correctional services
- the legal community
- ethno-racial communities.

The low priority and poor funding afforded mental health and addictions was seen as



another example of systemic stigma. For that reason, public policy makers, planners, bureaucrats, and those who fund health services and research were also centred out as important target groups.

Targeting the media was also thought to be important. Recommended strategies include addressing the often inaccurate reports on mental illness and addictions that reinforce negative stereotypes, and encouraging positive stories about mental illness as a mechanism for health promotion.

An often repeated concern was that addictions issues would be ignored or subsumed under the focus on mental illness. Given the high prevalence of co-occurring mental health and addiction problems, their profound impact on individual and family health, and high levels of disability that can result, the Commission is cautioned to ensure that this issues remain a priority in its focus.

### ***Aboriginal communities require a culturally relevant approach***

The Aboriginal, First Nations, Métis and Inuit communities were repeatedly identified as priority groups requiring a unique and culturally sensitive approach and programs that reflect their distinctive history, religion, cultural beliefs and holistic world view. Targeting aboriginal elders, healers and helpers is seen as a first priority. To be effective, survey respondents felt that programs need to be developed from within the community and delivered by peers who can model hope. A number of respondents felt that the balanced, holistic, wellness and recovery-focused approach of Aboriginal and First Nations communities, which emphasizes our shared 'human-ness', spiritual faith, the importance of family and community, holds promise for all Canadians.

### ***MHCC - Directed Media Campaign***

There was broad and enthusiastic support for the Commission to undertake a nationally focused, multi-media campaign designed to educate the public about the signs and symptoms of mental illness, dispel the myths, and change the attitudes of the general public. Those respondents urged that the Commission move quickly to engage experts to design and launch a social marketing campaign using electronic and print media, billboards, posters and brochures. Given its visibility, profile and budget, the MHCC was seen as uniquely positioned to take a leadership role and then share its resources with the provinces and with local groups conducting their own anti-stigma initiatives.



Some respondents believe that changing public attitudes will result in improved experience for people living with mental illness and addictions. Many felt that the use of advertisement and public service announcements was a highly successful approach. Conversely, a small but significant number of respondents felt this approach held little promise and that media-based anti-stigma initiatives served no benefit. Again, it is important to note that the many experts we interviewed do not support such broad-based campaigns, given the high cost of program delivery, their lack of specificity in messaging and audience targeting and the limited impact they have on improving quality of life and on sustained behavioural change.

### ***Measuring Impact***

The number of responses to this question would appear to suggest a fairly significant degree of evaluation activity, but the responses themselves indicate the contrary. Although some anti-stigma and education programs do include an evaluation component the vast majority of activities are not being evaluated in any formal way to determine if they are having the desired effect. That lack of evaluation appears to be a function of incomplete research knowledge and skills as well as limited fiscal and human resources. Programs delivered by larger agencies or those which are university or hospital-based are more likely to include research and evaluation.

Many respondents described *what they would do* if they were to evaluate their campaigns, *rather than what they actually do* at present. The following is a small sample of the wide array of ***tools and approaches*** identified:

- experience of stigma surveys
- stigma coping scales
- pre-post event assessments of changes in knowledge, attitudes and behaviour
- public opinion surveys
- focus group testing

Respondents also described the ***measures of success*** they would employ when evaluating anti-stigma campaigns. Those measures can be classified as follows:

- ***Output measures*** quantifying the amount of activity (e.g. web hits, requests for presentations)
- ***Outcome measures*** related to:
  - ***the quality of life*** enjoyed by consumer/survivors (e.g. increased social inclusion, increased employment, reduced focus on illness)



A Time For Action: Tackling Stigma and Discrimination - MHCC

- **public knowledge/awareness/attitudes** with respect to mental illness and the mentally ill (e.g. reduced experience of discrimination)
- changes in **social policy**
- changes in **media coverage** of mental health issues
- **public response** to anti-stigma messages (e.g. increased self-disclosure about experiences of mental illness)
- **other** socio/cultural norms and behaviours (e.g. reduced wait times for mental health treatment, increased willingness to seek help)

Given that diverse range of tools and approaches for measuring the impact of anti-stigma activities, any comparison between programs is currently impossible. The importance of building an evaluation culture, and of using standardized outcome measurement tools, is critical to the creation of a shared knowledge-base.



## Key Informant Interviews

The Consultant conducted 15 semi-structured interviews with leading experts in stigma research and/or program delivery<sup>9</sup>. Experts were asked to:

- Identify priorities and first steps for the Commission
- Provide best advice and identify pitfalls to be avoided
- Identify the essential elements of a comprehensive strategy and which groups should be targeted
- Suggest how to measure success
- Recommend essential readings and leaders in the field.

There is a remarkable level of agreement with many of the priorities identified by Canadians through the survey. However, there were also significant differences between survey respondents and experts in the methodologies recommended. Ten overarching themes emerged:

1. Be Big, Bold and Visible
2. Plan for action
3. Think big – Act small
4. A comprehensive strategy must be multi-faceted
5. Evaluation and research is limited – help it grow
6. Measure success
7. Work in partnership
8. Contact works
9. Target your efforts
10. Media require a special approach

### Be Big, Bold & Visible

Experts agree that the establishment of the MHCC represents an important watershed opportunity for Canadians. Stigma and discrimination is felt to represent the most significant barrier to treatment and recovery. A national focus on mental illness and addictions will increase visibility, communicate a sense of value, articulate a shared vision and mobilize the community to act in a coordinated manner. Experts advise the

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<sup>9</sup> A list of experts interviewed is included in Appendix D.



Commission to embrace its leadership role, to be bold in communicating its vision and strategic, targeted, clear and concise about what it intends to accomplish.

### **Plan for action**

Although there is a strong appetite for quick action, most experts recommend that the Commission take its time to create a strategic action plan with specific targets and measurable outcomes. They encourage the MHCC to address the structural barriers and systemic issues that deny people with mental illness and addictions the same access to services and resources as those with other health concerns. At the same time, if it is to be effective, the Commission must move beyond the role of a 'planning body' that recommends change, and become an organization which serves as a catalyst - by aligning its resources to deliver on its stated priorities, evaluating its impact, marketing its successes and revising its strategic plan based on results.

### **Think big - Act small**

Experts encourage the Commission to 'think big' but to act in small decisive ways that will build many successes in order to gain momentum and develop 'a sense of the possible'. While many Canadians expressed a strong desire for the MHCC to undertake a sophisticated, broadly-based, multi-media social marketing campaign targeted at changing the attitudes of Canadians most experts cautioned against doing what is 'sexy' but does not yield the greatest results. Some experts felt that a broadly-based mental health literacy campaign, intended to teach the general public the signs and symptoms of mental illness and to convey the notion that mental illnesses are treatable, is a valuable approach.

Others emphasized that the value of promoting mental health literacy is costly, difficult to evaluate and that, even if it is successful in changing attitudes, is unlikely to result in meaningful behavioural change that will improve the quality of life for people with mental health issues. It is the conclusion of the majority of experts that a more strategic approach is to use social marketing tools and the media to promote the Commission and engage the public as partners in reducing stigma and discrimination. Given that one in five Canadians is directly affected by mental illness, this may be a highly successful approach.

### **Elements of a comprehensive anti-stigma strategy**

A National Plan which is targeted, tested, has clear base lines and is well researched is



considered by the experts interviewed to be the cornerstone of a comprehensive strategy. Recommended program elements include:

- Involvement of consumers in a leading role
- Clear goals and specific outcomes
- Direct peer-to-peer contact strategies which are solution-focused
- Culturally relevant and age appropriate approaches
- Targeted and segmented strategies
- Strategies which:
  - Dispel myths of violence, incompetence, impulsivity and chronicity
  - Focus on reducing discrimination
  - Enhance rights and entitlements
  - Include a media focus – industry guidelines, positive normal portraits of people with mental illness
  - Focus on wellness and recovery

### **Evaluation and research is limited. Help it grow**

While research in the area of stigma and discrimination is limited, there is an emerging knowledge base that can provide guidance and direction to the Commission. There are many anti-stigma initiatives underway world-wide, delivered by impassioned, well meaning people. In the absence of well designed research and evaluation, however, there is a lack of evidence to build upon within the Canadian environment. Experts encourage the Commission to use the scientific evidence related to what is known to work, and to contribute to the development of a culture of research innovation in which multiple approaches are taken, evaluation is built into their design, and the findings are then shared to enhance understanding of what works and what doesn't. Building linkages with international researchers will also foster knowledge exchange and uptake.

### **Measure Success**

Measuring impact is widely agreed to be an essential element for aligning programs for success. Experts noted, however, that governments are often anxious to achieve 'quick hits' and 'early wins' and cautioned the Commission to manage expectations about its ability to produce rapid results. Program evaluation, using pre and post-measures tied to specific objectives, can be used as a short term indicator of success, but stigma reduction is a complex, long-term task which must be measured over many years.



Before undertaking its educational and advocacy efforts, the Commission and its partners are encouraged to establish benchmarks and success indicators, clearly tied to the desired outcomes of its activities. Stigma research has identified a growing number of behavioural measures, including:

- Improved social inclusion
- Social distance scales (in use for over 100 years)
- Attribution questionnaires
- Recovery scales and life satisfaction measures

Other resources are available through the Chicago Consortium for Stigma Research, which has developed a listing of commonly used standardized assessment tools<sup>10</sup>, and through English sources, where they are using three different annual measures to evaluate the impact of their multi-pronged approach. Those measures include: public attitude surveys, media content analysis (i.e. positive vs. negative reporting) and consumer evaluations - with 1,000 consumers reporting their experience of stigma and discrimination.

It is important to note, however, that attitudinal change has not been strongly tied to either affirmative behaviour change or enhanced quality of inclusion - making this measure less robust in assessing positive program impact.

By using standardized tools aligned with program goals, monitoring media stories (both positive and negative), website hits and down-loads, consumer evaluations (including their experience of stigma and discrimination) life satisfaction measures, tracking changes in public policy, changes in funding for mental illness, employment, involvement in education programs, etc., the Commission will be able to demonstrate the effectiveness of its efforts. It was also suggested that the Commission may be able to embed survey questions focused on stigma and discrimination into currently existing Stats Canada surveys such as Canadian Community Health Survey<sup>iv</sup> and various Labour Surveys. Given the high degree of integrity, public approval and participation in Stats Canada surveys, the skill of their researchers, training of their polling staff and breadth of their sampling (130,000) along with the ability to cross reference across disabilities, age, gender, socio-economic status, education and

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<sup>10</sup> <http://www.stigmaresearch.org/publications/measures/>



geographic region there would be a potent data field for researchers to mine. It may also be significantly less expensive process for benchmarking than undertaking a separate MHCC poll.

### **Work in partnership**

Experts agree that working in partnership with Canadian leaders and local community groups is the most effective way to proceed. Programs delivered locally have the greatest impact and local groups have the knowledge, penetration and ability to mobilize the volunteers required to mount an effective campaign. Experts also acknowledge that what is often lacking is coordination, and the fiscal and human resources necessary to deliver sustained, ongoing programs. A lack of program funding (by every level of government), limited corporate sponsorship, and reduced charitable giving are all examples of stigma and discrimination which the Commission needs to target in order to mobilize the capacity of the community to act. Experts advise the Commission to use its leverage and authority to coordinate efforts, to create matching grants and sponsorship programs and to build multi-sector partnerships in order to support program delivery for greatest impact. The Board will achieve the greatest traction by serving as spokespersons, identifying and recruiting champions, working with lead organizations and encouraging consumer groups at the local level to try and to evaluate innovative approaches.

### **Contact works**

There is expert agreement that contact, without question, is the most effective means of addressing stigma and reducing discrimination. Education efforts must be targeted and segmented, solution focused, with concise messaging and a clear call to action.

The most effective contact strategies share the following elements:

- Delivered by peers (i.e. students to students)
- Accurately reflect the impact of illness, the challenges in finding help, the journey to health and the message of hope that recovery is to be expected
- Delivered in small groups in local communities
- Disabuse the audience about pervasive myths related to mental illness (e.g. that people with mental illness are violent, impulsive, and/or incompetent)
- Allow opportunity for repeated contact and discussion
- Target the heart and not just the head – build empathy, rather than knowledge alone
- Focused on changing behaviours and not attitudes (For example hiring and



housing practices)

- Normalize mental illness as a shared condition
- Provide accurate information delivered by credible person
- Provide opportunity for repeated positive contact to people with mental illness and addictions issues (e.g. in the work place)

Because repeated, close peer-to-peer contact is so effective, understanding the mechanism and circumstances that allow some people to disclose their illness becomes an important element of building capacity for action. The Centre for Addiction and Mental Health cautioned the Commission, based on its own experience, to take great care in how it treats real people (including celebrities) when using them in public campaigns to ensure it is done ethically and with respect.

### **Target your efforts**

The Commission is encouraged to target its efforts and to consider focusing, initially, on groups with either the greatest influence or those with the greatest power to limit opportunities for inclusion. There is an emerging international trend away from education and toward activities that enhance consumers' civil rights and legal entitlements. Just as we found in the Canadian on-line survey, the following groups were most frequently identified by the experts:

- Health and mental health service providers
- Emergency responders (police, ambulance and emergency department personnel)
- Schools (starting early to build acceptance, enhance knowledge, and provide teachers with the tools they require to identify and direct students in need)
- Policy makers, public health, social planners and funders
- Families, caregiver, parents and friends (to support recovery)
- Social service personnel (Children's Aid, welfare and disability workers)
- Corrections, legal and court workers
- First Nations and Aboriginal communities
- Immigrant and ethno-cultural communities

Friends, caregivers and family are also seen as an important target group, based on research which demonstrates that people with supportive and accepting social networks recover faster, have less disability, do better and stay healthier. The experts also agree with Canadians that there are some groups (such as First Nations and



Aboriginal communities) which require a unique, culturally-specific approach, developed and delivered by community leaders.

### **Media requires a special approach**

The media are identified as essential target groups, both as a mechanism for conveying positive messages, and as an important source of negative portrayals of people with mental illness and addictions. Protest strategies such as “media watch’ programs which include the establishment of industry reporting standards, are seen as effective in challenging inaccurate and unfair images of mental illness and addictions. At the same time, efforts at building positive relationships with the media and encouraging main stream stories of hope is seen as a means of achieving broad reach and building mental illness and addictions into the general lexicon. Some jurisdictions (UK, USA, Australia, and New Zealand) have also created media awards and scholarships to encourage positive reportage.



## Recommendations for the MHCC:

***"Be the change you want to see in the world" Mahatma Gandhi***

The MHCC is faced with a unique challenge and enormous opportunity of harnessing the energies of an eager public without being overwhelmed by an insatiable appetite for rapid action. The following recommendations are intended to balance a need for strategic planning with opportunities for swift action on important priorities.

### 1. Create a clear vision

The Commission's first priority should be to **articulate a clear, simple and enduring vision** which included the following elements:

- ④ Consumers/ service users are the leaders
- ④ Contact is the method
- ④ Wellness and recover is the goal
- ④ Hope is the message
- ④ Engage the heart and not just the head

### 2. Engage consumers/users in a leadership role

The MHCC can demonstrate its commitment to placing consumers/users at the centre of a reformed system of care by actively engaging them to take on a leadership role in shaping the planning, development and content of its anti-stigma discrimination strategy. It is encourage to immediately establish an Advisory Committee in which consumers form a majority role, researchers are collaborative partners and senior champions demonstrate the high priority given to this initiative. By developing linkages to local, regional and national consumer networks the MHCC can create an essential reference group for informing messaging and testing approaches to its marketing materials.

### 3. Establish clear goals

Using this vision the Commission can then **establish bold goals** and is encouraged to take a **strong national leadership** role in creating change. The change required is not only attitudinal but will result in behavioural change that **addresses systemic inequities and removes barriers** for full and equal participation for people with



mental illness and addictions. Build a strategic planning process which integrates stigma and discrimination reduction into the activities of all MHCC Advisory Committees with a focus on systemic change.

#### **4. Convey a shared understanding amongst mental health leaders**

There is a shared agreement that stigma is an enormous, pressing problem however there is currently a lack of agreement about how stigma and discrimination can best be tackled. Creating a wellness and recovery-oriented system of care is a priority goal for the MHCC. Although recovery is a unifying concept which unites consumers, families, service providers and policy planners there is currently no universal understanding of what this means, how it is accomplished and measured. The Commission is encouraged to take steps to create a shared understanding of these important elements, developing key messages regarding stigma, discrimination, wellness and recovery and communicate them broadly. It is unlikely that there will be universal agreement and the MHCC is encouraged to work closely with those who are in alignment with its vision and goals, build momentum and bring others along by demonstrating success.

#### **5. Promote the Commission as a catalyst for change**

There is broad interest and extensive leadership already in place. Use the skills and expertise of social marketing to develop the profile of the Commission with the community and your stakeholders. Use the power of personal contact and story telling to put a human face on mental illness and communicate the challenges the Commission will take on. Bring together the brightest, most creative and best minds to help us catch the attention of the community and engage them as partners in change. Convene an expert panel "Blue Sky Council" to guide the MHCC's message development.

#### **6. Build a culture of research**

Create benchmarks and success indicators at the front end to align with the vision and stated goals of the MHCC. Build on currently existing data gathering mechanisms such as Stats Canada. Make your measures media worthy by sharing survey findings with the public. For example if reducing the experience of discrimination is a priority goal then measure the current experience of consumers as a base-line. If encouraging the 1/5 Canadians affected by mental illness to discuss their experience with their friends and colleagues then measure the current level of comfort in disclosure, barriers and



enablers. Make your benchmarks and success indicators action oriented. Make what you measure matter.

## **7. Plan - hurry up and slow down**

Develop a process for engaging consumers in a leadership role and establish a working group to develop a multi-pronged approach to addressing stigma. Through this planning process the Commission can identify those lead partners or agencies that can best deliver priority program areas. Develop a multi-prong approach which includes:

- Development of contact/education strategies
- Establishes priority targets with specific messages
  - Focus on youth and health care professionals first
  - Work with First Nations/ Aboriginal/Inuit/Métis communities to develop culturally relevant approaches
  - Focus on local delivery of programming
- Media engagement/media watch
- Ombudsman office – policy watch

## **8. Build on existing National leadership to advance high priority areas**

The importance of working with existing leaders and building community partnerships was clearly identified. There are a number of National organizations/ initiatives currently underway with strong leadership that the Commission can engage to move forward quickly on priority areas. Some examples include:

- Canadian Collaborative Mental Health Initiative<sup>lvi</sup> – to develop an anti-stigma strategy focused on health care professionals
- MindYourMind<sup>lvii</sup> – youth focused, internet-based program with extensive reach into this important but difficult to access sector
- Canadian Alliance for Mental Illness and Mental Health<sup>lviii</sup> – to integrate Mental Health Literacy Project into a comprehensive anti-stigma strategy
- National Native Mental Health Association – to engage the Aboriginal community to define priorities and shape anti-stigma messages unique to these communities
- Global Business & Economic Roundtable on Addictions and Mental Health<sup>lix</sup> – to address workplace issues.



- Canadian Associations of Chiefs of Police<sup>lx</sup> – to address emergency response training for people with mental illness and addictions

## **9. Build national and international linkages**

The Commission is advised to create linkages with research experts and anti-stigma/discrimination program leaders within Canada and internationally and cultivate knowledge development and exchange. Through its participation in the International Initiative for Mental Health Leadership the Commission established positive working relations with international leaders working on stigma reduction programs.

## **10. Be Big, Bold and Creative - Act quickly**

Given the efficacy of contact strategies delivered on a peer-to-peer basis establish a Consumer Grants and Scholarship Program for local consumer-based initiatives to:

1. Support contact strategies
2. Align activities with MHCC priorities
3. Build community capacity
4. Promote multi-sector funding partnership
5. Provide access to resources – in kind resources (marketing, creative, research)



## APPENDICES

### APPENDIX A INTERNATIONAL ANTI-STIGMA/DISCRIMINATION PROGRAMS



### APPENDIX B – LITERATURE REVIEW REFERENCES



### APPENDIX C –CANADIAN ACTIVITIES – LISTED GEOGRAPHICALLY



### APPENDIX D - KEY INFORMANT INTERVIEW LIST



- 
- i References available in Appendix B
  - ii Weiss and Ramakrishna (2004)
  - iii Mental Illness Research Association
  - iv Everett (2006)
  - v Lemert (1951)
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## A Time For Action: Tackling Stigma and Discrimination - MHCC

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- xxx [www.btslessonplans.org](http://www.btslessonplans.org)
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