



## The Hallway Group: Consumer Reference

Toronto, June 27, 2009

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### Introduction and Background

#### Micheal Pietrus, Director Anti-Stigma/Anti-Discrimination Initiative

Thanks to the participants for your openness and sharing the previous evening.

#### Like a pebble dropped into a pool

We hope this meeting is the beginning of a process that will grow in expanding circles outward. Because no one person has all the answers, the foundation of our approach is to engage people in a free-flowing process. We hope you will continue to expand the circle by reaching out to people you know, telling them about our conversations and initiatives, and taking the information you learn in your own networks back in to the MHCC.

#### Context for this meeting

There is now a table for health care providers to bring their experiences and perspectives to the MHCC; it is imperative to have a similar mechanism in place for people with lived experience of mental illness. This group has the knowledge necessary to drive the Commission's anti-stigma programs, and this meeting is a first step in what we envision as an ever-expanding process of reaching out.

#### Our common cause

Our goal is one we share with you: to make a difference in the lives of people living with a mental illness or mental health issues. Critics on the sidelines will not help us move forward, and our work to date has not been as effective as it could have been because of fragmentation. Rather than laying on programs from the top down, we need to engage people like you, with knowledge, experience and leadership from the grass roots or community level. This is critical. Unless we are one unified common voice working toward this common cause, the public will not take us seriously.

*We can only do it if we all work together and if you get engaged.*

#### Parameters of this group

Stigma is the starting point, but should not limit the scope of this meeting. It is also fine to discuss other areas, and identify gaps that the MHCC may not be currently addressing.

#### Stigma and how to combat it

People who have experienced mental illness and mental health issues do not need to be convinced about stigma; you have lived with its consequences and are engaged in trying to change it. It is the general public that needs to be convinced, and our challenge to change people's attitudes and behaviours.

Changing attitudes is a complex challenge. People are better informed than it may seem. They generally understand the biological factors and treatments involved in mental illness. Paradoxically,

increases in knowledge can lead to an increase in stigma. This can be explained by the shift from neutral when uninformed to a firmer position, positive or negative, once information has been given. Most people move toward more positive views, but a smaller group moves to take negative views. Thus trying to inform and engage people carries some risks. It is still an important task, but we must be prepared for a backlash.

This phenomenon is one key reason not to conduct a broad-based public awareness campaign. Not only is it expensive to implement, but the results in changed knowledge are short term, and there are the risks for some negative effects. A better approach is to engage people at the community level, where the information will sink in and stick, and the chance of success is greater. As a result, the MHCC is beginning its anti-stigma activities by gathering information about grass roots initiatives across the country, with a plan to build tool kits based on community programs that are working.

### **MHCC efforts against stigma and discrimination (see overview on pp. 6-7)**

The Commission is connecting with programs and organizations across the country to be future demonstration sites for reducing stigma among two populations of specific need: health care providers or young people. The intent is to be a catalyst, providing strategic resources that will allow the initiatives to get started and expand, with a focus in this first phase on evaluation. Although at times it may seem that we are not making much of a dent in people's attitudes, we are inspired by other movements such as AIDS and breast cancer. They have shifted public attitudes dramatically in recent years, and we know we can make a similar difference. But the only way we can do it is to work together.

### **Phil Upshall, Director of Stakeholder Relations**

#### **Building a common voice**

One of the government-mandated activities of the Commission is to set up and run a 10-year anti-stigma program. The funding mechanism behind this provides for continuity and an opportunity. The stronger our common voice (which can be seen as a threat to government), the more power and attention will be paid to this issue. The issue of terminology (consumer, survivor, lived experience) remains unresolved, but it is the action that counts. Let us agree not to get caught up in the terms and to move forward beyond that discussion.

This excellent group can help us find new voices: people with opinions who are prepared to state them, people who have not been part of the MHCCs discussions and your networks will be very important in this regard. The Health Care Providers' table is providing a needed perspective, but the grass roots voices at this table are the important ones. We hope this group can meet on a regular basis; it can be an incredible catalyst for change.

*The Commission will work best when it is informed by honest straightforward voices, and a broad range of networks growing from the nucleus here today.*

## Group Responses to Introductory Comments

### Question and response from Mike Pietrus about roots of stigma

How does increased knowledge lead to increased stigma?

When the people who haven't given much thought to mental illness (the mushy middle) receive more information, they begin to shift and form opinions. For most people these are positive, but some will develop negative stereotypes. We're trying to create a larger critical mass of people with positive views to set the public agenda.

A single incident can set our work back, but it can also be an opportunity. After a violent incident involving a man with mental illness in Calgary, a newspaper talked to experts before reporting the story, and took a balanced approach to its reporting. It stressed that this is a rare occurrence, and that stigma itself could have stopped the person from getting the help that might have prevented this tragedy.

*There are effective and non-effective approaches to literacy, but literacy per se is not an agent of change; contact is. It can show people they have nothing to be afraid of.*

Contact is critical, but still complex; brief contact can have negative results. Heather Stuart, the MHCC Senior Consultant on Anti-Stigma Initiatives, says that it's the interaction, hearing life stories, having time to talk things through that makes the real difference.

### Combating stigma: a combination of strategies

Anti-stigma initiatives should not be confined to the media; there needs to be a more complex matrix of strategies. And even with the media, the approach needs to be much more comprehensive than simply advertising. A campaign should be multi-faceted and approach each particular audience with a different style and vision.

Many countries have had trouble getting people to change behaviours, possibly because they are just going after the general public and not targeting their message tightly enough. Some countries wish they had reached out to health care providers, as the MHCC is doing.

*We need to target our message and support our public education initiatives with advocacy and mobilization of a social movement. Speaking with one voice is paramount.*

Providing information to the public seemed a successful approach in the case of AIDS, where misconceptions were changed by information; the more we learned, the more our attitudes shifted. However, advocacy and mobilization initiatives also supported awareness raising; as knowledge and litigation increased, so did acceptance and understanding. The gay community used their influence commercially to reduce the price of drugs and developed a social movement to prop up their public awareness efforts.

### The role of legislation

Changing attitudes does not necessarily change behaviour; only legislation can make this happen (as in non-smoking policies). According to Heather Stuart, the single most effective way to create change is

through legislation. The MHCC Mental Health and Law Advisory Committee is looking into using legislation in general as well as specifically to enforce rights and safety in the workplace. It is easier to have effective legislation if the public is prepared in advance to accept it. Although we cannot legislate understanding, compassion, decency, and kindness, education can create the groundwork.

### **Stigma in the criminal justice system**

The MHCC is developing an anti-stigma presentation and engagement initiative for the Canadian Justice Council (police, prison guards, probation workers, social workers). There are diversion-type programs, as in Alberta, that provide community support people for a person with mental illness who would otherwise serve time in the criminal justice system. This is important, because systems lead to labels: people picked up by police can get labeled as either criminal or consumer after just two visits to either jail or hospital. Some end up in jail because of the legal system itself, advised by lawyers not to invoke the Mental Health Act if they are charged with a crime because the time spent incarcerated in hospital is likely to be longer than the time served in the criminal justice system. Correction institutions are the new asylums.

The Minister of Public Safety has asked Corrections Canada for changes in this area. Paramedics, rather than police, should be the ones who pick up people with mental illness; sending trained police officers can set off some people's fears of police uniforms. People should not be held in solitary in correction facilities (or hospitals either).

It is also necessary to recognize the mental health needs of the staff in corrections; they too experience trauma and are struggling. We have to be more inclusive and accepting of the people we are trying to change.

*The us/them mentality has to change.*

### **Background and Overview of the MHCC: Micheal Pietrus**

The Mental Health Commission of Canada (MHCC) grew out of the *Out of the Shadows* report. It received funding in March 2007, and its Board met for the first time in September of the same year. It is a not-for-profit organization, operating at arm's-length from government, whose mandate is to improve the quality of life for people living with mental illness and mental health problems. It does not provide services, but acts as a catalyst to help bring about action for reform, such as promoting collaboration amongst mental health agencies that are working in isolation from one another, to help them meet their common goals more effectively.

Eight Advisory Committees provide the Commission with expertise from across the country in the areas of Service System; Science; Family Caregivers; Mental Health and the Law; Workforce; Children and Youth; First Nations, Inuit and Métis; and Seniors. These committees are engaged in a total of 24 projects in areas such as human rights, and a vision for child and youth mental health. There is no separate consumer advisory committee, but there are consumers on all the committees as well as on the Board.

The Commission's original key initiatives mandated by government are to develop a national mental health strategy, an anti-stigma initiative, and a Knowledge Exchange Centre. There are now two

additional key initiatives: a national homelessness research initiative and the Partners Program, aiming to build a national movement around mental health and mental illness.

### **A national strategy for Canada**

#### ***Making the case***

The World Health Organization has predicted that by 2020 depression will be the second leading cause of disability worldwide, second only to heart disease. In Canada there is an estimated \$33 billion per year of lost productivity due to mental illness, and yet it is the only G8 country without a national mental health strategy. This can be explained in part by our constitutional makeup; the delivery of health care services is a provincial/territorial rather than federal mandate, and hence we have a patchwork quilt of policies and services. A strategy will need buy-in from each of the parts, but work for the whole.

#### ***Progress on the national strategy***

The MHCC plans for a national strategy, informed by responses from the public, focus on health and social outcomes for people living with mental illness and mental health issues. After gathering responses to a draft goal framework (the WHAT), the national strategy team is pulling together a final framework. They will then move into developing the implementation steps (the HOW), and build buy-in from the Provinces and Territories.

### **Anti-stigma/Anti-discrimination activities**

#### ***Mount Royal College presentation***

A pilot Anti-Stigma presentation to address misconceptions and stereotypes about mental illness was offered at Mount Royal College in March 2009 to journalism, nursing, social work and justice students. The speakers included an international media and popular culture expert, people with experience of mental illness, a journalist, and a daughter of a father with schizophrenia. Using surveys designed by Heather Stuart, the attitudes of the audience were tested before and after the presentations. The presenters who resonated most with the audience were the consumers; the changes people said they would make related to language, and being more thoughtful and open minded. In general, neutral and stigmatizing beliefs about making friends with someone with mental illness were lower after hearing the presentations, and non-stigmatizing beliefs about hiring someone with a mental illness increased. Participants preferred stories and personal contact to less personal communication.

Experiences from group members at this meeting support these findings. DVDs were found to be not as effective as face-to-face contact and the potential for asking questions. In addition, effective strategies with consumer presenters include training, and offering the presentations on a Thursday so that they can check in with someone on the Friday if needed.

### ***Developing a network of community-based programs***

#### ***Stage 1 Target populations***

The first stage of the anti-stigma/discrimination initiative targets two key populations: children and youth, and health care providers (the next stage will target the workforce). Because childhood and adolescence is so often the time when mental health problems first present, it is important to break

down stigma - amongst young people themselves and those who work with them - so that young people will be comfortable about seeking help. In terms of health care professionals, this group also has stigmatizing beliefs, with much of this on the front line. It must be addressed in order that people can access the help they need in a safe environment. In general, for both groups, media can be an important agent of change.

#### *Activities to date*

After a broad-based meeting in 2008 developed a consensus statement on stigma, two more meetings built consensus on how to move forward in the areas of child and youth and health care providers. A recent request for expressions of interest in these areas elicited 248 proposals. Dr. Heather Stuart helped develop the selection criteria, and led a meeting June 1 of an impartial selection panel of international and national experts (including consumer expertise). The panel selected 22 proposals directed at health care providers, and 24 directed at youth, all of which met the criteria of best or proven practices that can be replicated across the country, and in particular an engagement component, since direct contact with people with mental illness is a key to success.

#### *Evaluation*

The MHCC will evaluate the selected programs and help develop them further, and the lessons learned will inform the newer initiatives. There are still outstanding issues to understand, and it is hoped that evaluating the projects will help us learn some answers. For example, is presenting a video as effective as hearing from people in person? How much does discussion effect a program's effectiveness? What components are needed to make a program work?

#### *Next steps*

Once the programs are confirmed, the remainder of Phase One will consist of getting them launched, helping them to connect with one another, and creating tools that will allow other communities to duplicate the initiatives. The MHCC plans to create a network amongst the programs it selects, a strategy the Roslyn Carter Centre in Atlanta will try to replicate. The next phase will involve identifying a second round of programs to work with, according to the lessons learned from the first group. Following this second round, the Initiative will identify gaps, and then develop new projects to address those gaps. The MHCC will act as a catalyst to get the projects set up, but the aim is for them to run on their own.

#### **Knowledge Exchange Centre (KEC)**

This web-based initiative is still in its early stages, but is expected to get more traction later in this year. Input from consumers about the content of the site will be critical. It will have a Knowledge Transfer function providing up-to-date information about the latest treatments and medications. In an age where information is rapidly expanding and easy to access but not always easy to tell if it is trustworthy, it will be a credible source of information from research, information about support groups, where to find more information, and where to get help. There will also be a Knowledge Exchange function, with a "network of networks" allowing users to share information. Since the MHCC has a ten-year mandate, plans will be needed to ensure the KEC is sustainable and to consider how it will work in different provinces.

### Homelessness Research Initiatives

Research shows that 25-50% of homeless people have mental illness and 50-70% of these also abuse substances. 11% of homeless people meet the criteria for Schizophrenia, as opposed to the national Schizophrenia rate of 1%. Research from Simon Fraser University demonstrates substantial cost savings when homeless people move into adequate housing with supports.

Group Comments: It is important to acknowledge that homelessness can be invisible, and that there is a causal factor in these statistics; being homeless can lead to severe physical and mental health problems. The impact on health of poverty and other social determinants must be part of the Commission's understanding of the issue.

*"Never underestimate the power of poverty to make you crazy."*

The Commission received \$110M in Feb. '08 from the federal government for 5 projects in different provinces, each focusing on a particular target issue or population: Vancouver – mental health and addictions; Winnipeg – urban Aboriginal population; Toronto – people whose first language is not English; Montreal – services for homeless mentally ill people in the province of Quebec; Moncton – shortage of services for English and French speaking people with mental illness who are homeless.

### Partners for Mental Health

The vision for the Partners initiative is a national network dedicated to improving mental health services and supports across the country, shining the spotlight on mental health issues, and bringing them out of the shadows forever. It will be comprised of volunteers from every part of the country, including organizations, unions, communities, and the grass roots. The Commission will catalyze the movement, but it is expected to take on a life of its own. It is hoped the movement will be as successful as the movements for AIDS and breast cancer have been, with education campaigns, advocacy, raising funds, volunteering in health organizations, and getting people to talk about their experiences.

*"Never underestimate the power of a small group of committed people to change the world. In fact, it is the only thing that ever has." ... Margaret Mead*

This initiative is now getting underway. Staff is on board, and a Director is being hired and will be announced shortly. Lesley Southwick-Trask, a consultant working on this initiative, joined the meeting at a later point; that discussion can be found starting on p. 11 of this report.

### Mental Health Partnerships of Canada

This national charity, an alliance of the MHCC with the Canadian Psychiatric Research Foundation and funded by large and small donors, is a separate body from MHCC. It can provide charitable receipts which the Commission is unable to do.

### General progress of MHCC to date

In the Commission's short history since March 2007, much has been accomplished. There is now a staff of 35, with the head office established in Calgary. There are 8 Advisory Committees running a total of 24 projects, a draft National Strategy Framework, a direction established for the Anti-Stigma Initiative, all Homelessness projects underway, and action begun to develop a volunteer movement and a national charity. In addition, governments, social organizations, church groups, and general public are all becoming involved. It is essential to engage Canadians in our work, and very encouraging to see this starting to happen.

### Group Response to MHCC Overview

Besides the group discussion throughout the preceding overview, captured in the reporting above, there were also three specific points made in response to the presentation:

- In regard to the homelessness project, the MHCC makes the point that a homeless person is someone's child. In fact, every person with mental illness is someone's child.
- The Partnerships charity is problematic if it is raising funds to support new programs across Canada when the organizations already in place are scrambling to cover the costs of their existing programs.
- Not only are citizens becoming engaged, but money is being leveraged, another example of the Commission's catalyst role.

The rest of the response focused on the consumer role in the Commission's work, and in particular the consumer constituency vis-à-vis a national movement. There was general agreement that people with mental illness should be the starting point of any initiative to mobilize Canadians, and discomfort with the image of the Commission reaching down to the grass roots to build a movement rather than the movement developing organically out of the grass roots. One participant put more emphasis on creating a defined space for consumers to organize and provide input into the Commission's work, while another stressed the benefits of non-consumers and consumers working together, but in the end all seemed to agree that these are not mutually exclusive. There was a call for more explicit involvement of consumers in the MHCC, and a distinct Consumer Advisory Committee. The discussion is summarized below.

*We are pleased to partner, but we also need to develop our independence.*

### Help create the land for us to build on

The approach of sprinkling/embedding people who have experienced mental illness within committees rather than having a separate consumer advisory committee is not optimal. If there are two consumers within a committee, what traction will they have in a group of 20? Their power and advocacy potential will be neutralized. What is needed is funding to bring together elements of the consumer infrastructure across the country.

The MHCC is like an elephant, bigger than any of us. 2,000 people within New Brunswick would not feel they can connect with this agenda. They would be engaged if the MHCC were to create a climate for us to build our own state of land, our own movement; for now we lack the support to do this. The MHCC seems afraid to put all of us in one room in case we go off in a direction they don't want. A social movement is not the same as a national consumer movement; it blends everybody with their different interests, and is politically safer. Our agendas are also different: the social movement would talk about illness, but the consumer movement is more interested in independence liberty, creativity, the arts, literature. A national consumer movement requires a new architecture. It is a loyal opposition where the collectively can partner collaboratively with other groups and have space for critique, opposition and militancy.

#### **Avoid "us versus them"**

On the other hand, we need non-consumers to be there to guide the process. We cannot ignore who is in power, and will not get anywhere if there are only consumers. We have to partner with non consumers, and use their skills in navigating this territory.

#### **Bottom up rather than top down direction**

We would not exist without partnerships and we need everybody working together, but the politics of those with power are different from those of the rest of us. There is a power in the MHCC, manifest in the way it frames its plans to develop a social movement, as if reaching down to those of us who are working on the ground, doing bake sales to stay alive. The notion of the MHCC going down and pulling us up, as opposed to building on the grass roots that are already there, is unsettling. The momentum should go in the opposite direction, with the grass roots mobilizing to build the Commission from the ground up, and consumers as managers and in other staff positions. The question should be how to provide the consumer movement with strength, rather than how to draw strength from it. The current choreography is disturbing, and the MHCC needs to work with the consumer community so that we can all understand this better and feel we belong.

*The social movement should emerge from a strong consumer movement.*

#### **Commission response to this discussion**

##### **This is the reason we have brought you together**

This discussion illustrates why everyone is here today; it is the beginning of the forum we've been talking about. These opinions need to be on the table, and they are legitimate topics for the MHCC to address. It is the MHCC's responsibility to connect with grass roots organizations and individuals, who are all busy doing their jobs. Michael Kirby is right that we need to keep the spotlight on mental health issues, but the social movement has not yet coalesced. It has to happen from the ground up, and bring together fragmented forces as it gains momentum.

### A separate MHCC Consumer Advisory Committee or other body?

The Advisory Committees may be fixed now, but there are other options, such as the Consumer Council (group of consumers who are on MNCC Board and Advisory Committees) as the loyal opposition. Although there is not a health care providers' Advisory Committee, providers have immediate input to the people leading the initiatives by working directly with the directors. The same structure can work for consumers.

### Building both kinds of movements together

Is there room for both a robust consumer movement and a broad national movement that engages the Canadian public, including those outside the mental health sector? The movement needs to engage people outside the mental health sector and build from the ground up, while also building the consumer movement. We need to set up the groundwork for people to feel safe to come forward and for the public to be accepting, and to draw on support from the general public and bring them on board, but it can't happen in isolation or if we continue in separate fragmented directions.

*Together we can build a movement that strengthens the consumer sector and engages the broader public.*

### Lesley Southwick-Trask, on developing the Partners Program

Lesley joined the meeting by telephone to get a sense of the participants' feelings about the Partners initiative. As part of developing the initiative, the consultant team of which Lesley is a member, is trying to "build the hub that will be the virtual world in which Partners will operate". They see Partners as "a gathering voice for reform", a "larger citizen-based voice".

Michael Kirby's vision is for millions of Canadians using their collective voice to call for more attention to mental health issues and responses that are better aligned with people's needs. The movement needs to be organized and representative in order to apply political and social pressure where it needs to, and to include individuals and groups, and new disenfranchised voices that have no current vehicle for engagement. The challenge is to engage the public to raise the profile of mental health issues to the positions AIDS and breast cancer have attained by participation, volunteering, fundraising, education, and advocacy with a single voice.

Lesley's question for the group is what kind of movement they would want to be part of and how Partners can provide an environment to make that happen.

### Group response and discussion

*Does the Commission understand the concept of building the capacity of the consumer movement to draw in other people? It has to be at the centre of their approach.  
Grass roots initiatives are important, and the growth must come from the ground.*

Group members have concerns about the Commission organizing a broad social movement. It can seem like a threat to some existing organizations or communities of interest that may want to go in other directions. For many of us working on the front lines day to day, there's a sense that the Commission is more powerful than a local support group. Now it has deemed it would be good to have a social movement, and hence is trying to organize us in that direction. But we work from the bottom up, drawing on support from others, and starting with the people who have experienced mental illness and are most affected by the issues.

It does not seem logical for the MHCC to be building a Partners movement at this time. The priority is to build up the consumer movement first. The mental health business is all about power, and if a social movement is just individuals at large, it will not promote reform.

There is a lot of untapped expertise because people are working on the ground in their own organizations or doing their own thing. The places to start are the pockets of well developed organizations across the country. It is also necessary to normalize mental illness in everyday discussion. Without normalization we will not move forward.

#### **Appreciation from Lesley**

Lesley agrees: the consumer, not the Commission, should be in the centre. The Partners program is intended to be a support, to connect the dots, and to find out what's already working and how to link to it. The responses from this group have taken us light years ahead in putting words to our intentions; sincere thanks. Lesley will be contacting those members who have agreed to follow up conversations.

#### **Developing Terms of Reference**

#### **Discussion led by Romie Christie, Manager of Communications and Project Manager, Anti-Stigma/Anti-Discrimination Initiative**

##### **Background of this Group: MHCC context**

This historical groundwork that anchors this Group includes:

- Formation of MHCC and its Anti-Stigma program
- Identification of a need for a group like this, that can provide the MHCC with input on the Anti-Stigma program as well as on a broader range of issues
- Not part of MHCC, unaffected by MHCC thinking; reflective of the interests and advocacy activities of the consumer community
- A guide for the MHCC in developing policies and activities

##### **Background of this Group: Broader context**

Outside of the MHCC, there have historically been expressions of discontent from the consumer community about their feelings of not being heard. That was not the reason for developing this Group, but if it will help to address those concerns, that will be a positive, if unintended, consequence.

*Be careful what you ask for, but aim high.  
Aspirations need to be part of this.*

### **Mandate: Anti-stigma and more**

This Group was developed to inform the MHCC's anti-stigma activities from the perspectives of those who have experienced stigma and worked toward reducing it. There may also be opportunities to expand the group's scope to other issues as well. Beyond just reacting and responding about stigma, this group should also lead or influence the MHCC in general, and initiate discussions. We do not want to broaden our responsibilities to the point where they become too much, but it is possible to focus for now on anti-stigma while building toward a bigger role in future. In defining Terms of Reference, both the current role and aspirational role we're building toward should play a part. For example, our unique role could allow us to bring consumer leaders and funders together in order to help facilitate the change we're seeking.

### ***A work in progress***

This group should be seen as fluid, organic, with room to grow, and the scope to bring issues to the table when we feel we can make a contribution. We can be the ones to raise issues from our perspective external to the MHCC, or the MHCC can tap our expertise when it requires our input about issues such as Community Treatment Orders, for example, or funding of NGOs in relation to the national strategy. The MHCC Consumer Council will also provide input and feedback.

### **Way of working**

There is a double weight on us: this is our lives and there is a lot of at stake, but we also have step back and give a constructive, solid objective critique.

*We need to find the balance between passion and objectivity.*

Our working principles will include:

- Respect for people's opinions; we recognize that members will have different experiences in regard to mental health issues and varying opinions
- Honesty, keeping issues on the table instead of behind the table
- Making our meetings a safe and comfortable place to express opinions
- Allowing the MHCC to hear honest perspectives reflective of consumers

### ***Representative or reflective?***

We are a collection of individuals with our own leadership roles and mental health issues, yet common experiences through painful, difficult processes. We speak from the perspective of our own experience as well as what we've learned from engaging with other consumers. We are not representative in the sense of speaking formally on behalf of an individual or group, but we can stand in proxy for others who may not have the opportunity to speak out.

*Sharing information: contacts, connections, and common sense*

Our role is to bring information about our work here back to our networks, and to bring back to the Commission the information we've collected about consumer views, struggles, interests, advocacy activities. It will be possible to have confidential conversations within this group when needed, but we will raise awareness of the issues as much as we can. At the same time, we need to respect our networks' time and efforts and not put them into consultation overload; the information we share must be substantive.

*We can use a common sense approach for taking the pulse of our constituency.*

Recognizing we cannot reach the whole consumer constituency of the country, our consultation style will be casual; we will connect with our communities using natural structures (networks, community, groups) and existing processes (conversation, dialogue, newsletters, web, email) or whatever ways work for us and for them. We will not conduct polls or scientific or in-depth surveys, and may not tap the whole community, but can sample opinions and still get a sense of the thoughts of people we talk to. If a more formal approach is needed, we can discuss how to address this once we've begun to share the information with our groups. The MHCC is looking to this group to help it find ways to be inclusive. It will draw on the brain trust here and take its direction on how to get the message out so that no gaps are left.

**ACTION:** The MHCC will provide a summary of this meeting for members to share with their networks if they choose.

**Membership: acknowledging the voices that need to be heard**

We recognize that ours are not the only voices – there is also the Consumer Council, and voices missing from communities such as rural, underserved, Aboriginal, and diverse cultures and languages (included in the MHCC in different ways, but still gaps to continue to watch for). However, if this Group becomes too big, its tasks will be more complicated, it will have to subdivide, and will risk losing its focus. It is not in the best interests at this stage of development to expand the group; we need to gel as we are, and return to the gaps in future.

**DECISION:** In the interest of developing our own culture, for the present we will not be including the communities that should be here.

*There is a risk of becoming part of the problem if we perpetuate exclusivity by benign neglect.*

### Organizational structure

Both Phil Upshall and Chris Summerville are members of the MHCC Consumer Council (the internal MHCC group), and are ex-officio members of this group to maintain a liaison with the Council. Phil, who is also MHCC Director of Stakeholder Relations, is willing to help filter our messages to the MHCC, and facilitate the needs of this group to the MHCC.

Chris Summerville joined the meeting by telephone, to pass on his vision of this group as a reflection of the lived experiences of others and the consumer voice, and discuss the role of this Group with the meeting participants. The MHCC Consumer Council is wrestling with how to capture the diversity of the consumer community, a constituency critically important to a social movement. This group's role should be flexible so that it might serve as a reference group for other initiatives besides anti-stigma. For example, it could meet with Howard Chodos, Director of the National Strategy, or develop a template to gauge all MHCC initiatives in terms of their response to the perspectives of the consumer community. Participants added that the MHCC must model its own principles, serve as a mentor, and develop its own community.

### Meeting logistics

**DECISION:** We will plan on 2 face-to-face meetings plus 2 teleconferences per year, to be set up by Phil. We can communicate between meetings and organize special meetings as needed.

There may be a possible opportunity to hold the next face-to-face meeting in conjunction with the MHCC *Into the Light* conference planned for the end November/beginning December 2009 in Vancouver. The MHCC family will convene to discuss the national strategy, stigma, Partners program, and other initiatives. This will be explored further as the conference plans firm up.

The question was raised about an internal chairperson, or a point person who could organize in-camera meetings if the need arises. The general feeling is that this does not seem necessary, and that we should be professional enough to put on the table what needs to be on the table at the regular meetings. We want to keep this Table moving forward in a positive way.

**DECISION:** At this point, there is no need for an internal facilitator or chair from within the group. We can re-visit this question at the next conference call meeting.

**ACTION:** Contact information for all members will be circulated.

### Names and titles

#### *For this group*

In many groups and committees, the most important conversations take place away from the table, in the halls. We want to make sure we carry on those hallway conversations at the table, to bring our best thoughts and ideas to the task. Hence the suggested name: The Hallway Group, with an addendum to clarify its purpose, was selected with enthusiasm.

**DECISION:** This Group's name will be ***The Hallway Group: Consumer Reference***

### *For Anti-Stigma/Anti-Discrimination Initiative*

Background from Micheal Pietrus: The MHCC is looking for a new identity for its anti-stigma/anti-discrimination program, and a name that will resonate with and win over the general public. Some names previously suggested are Like Minds, Like Mine and Time to Change. How we frame and contextualize our initiative will be very important; being edgier and dramatic can sometimes be off-putting for the general public, and many names can increase stigma. It takes a long process to get the right name.

Suggestions from this group:

- Opening Minds; Changer les mentalités (from Joe Leger, a youth consumer)
- Changing Minds and Hearts
- Opening Minds: Change is possible

### **Au Revoir and Sincere Thanks**

This is a key group with significant observations that need to be discussed and followed through. The MHCC is committed to continue to bring you together. Many thanks from Mike Pietrus and the other MHCC staff for being here, for your contributions, and especially for sharing. This has been a tremendous start!

**NEXT MEETING:** Teleconference Sept. 24 or 25 (to be determined) at 11:30 a.m. Atlantic Time, 10:30 a.m. Eastern Time, 9:30 a.m. Manitoba Time and 8:30 a.m. Mountain Time

