Mental Health Commission of Canada

Anti-Stigma/Anti-Discrimination Planning Session

Summary of Discussions

December 1, 2008

Present: Ella Amir – Chair, MHC Family & Caregivers Advisory Committee; Lisa Brown – Workman Arts; Don Buchanan – Child & Youth Mental Health, CHEO; Romie Christie – Project Manager Anti-Stigma Campaign MHCC; Bernie Colterman – Director, CEPSM; Maria Luisa Contursi – Program Director mindyourmind.ca; Simon Davidson – CHAIR, Child & Youth Advisory Committee; Ron Gravel – Statistics Canada, Mental Health Portfolio; Don Hewson - President HBS Marketing; Joe Leger - Children & Youth Advisory Committee NS; Jim Mintz - Director CEPSM; John Petitti - VP Strategic Planning and Social marketing practice leader, HBS; Mike Pietrus - Director, Anti-Stigma Campaign MHCC; Heather Stuart - Senior Consultant, Anti-Stigma Campaign MHCC; Chris Summerville - Schizophrenia Society of Canada; Denise Taylor - Director, Aboriginal Health, BC Interior

Absent: Anie Bélanger- Child & Youth Advisory Committee; Brenda Restoule – Co-Chair, Native Mental Health Association of Canada

Welcoming Comments and Introductions

Micheal Pietrus opened the planning session with the following points:

- The MHCC has been tasked with developing a 10 year anti stigma campaign. An operational plan has been developed as a blue print for a plan for action. HBS and Centre of Excellence for Public Sector Marketing (CEPSM) have been hired by the MHCC to help develop a social marketing campaign plan and strategy.

- A consensus meeting was held in September to help develop a vision, guiding principles and goals for an anti stigma campaign. HBS and CEPSM are now engaged in developing the plan and strategy.

- Research shows the best approach is not to launch a broad-based campaign. It is recommended that a targeted approach be used which includes focusing on specific groups and chipping away at the issues. Two target groups have been identified as the priority: Health Care professionals because patients encounter stigma from the first line of care, as well as Youth. It is important to get feed back and ideas from the participants at this meeting to help breakdown the barriers.

- The HBS/CEPSM team has been brought in to develop a social marketing plan and strategy, with today's focus is youth, tomorrow health care professionals. The goal of the session will be to validate ideas through the professionals in the field. HBS and CEPSM will lead the session.

Presentation, Research and Strategic Direction

John Petitti presented a summary of research and proposed strategic direction for the youth campaign (refer to Power Point Presentation). Key points included:

- What are the true motivations to bring youth to a point where they feel the need for change? The changes in behaviors truly occur with engagement. Advertising builds awareness but does not change behavior. What are the channels going to be? How do we support them?

- Priority Audiences for Year 1: Youth aged 12-18
- Health and Mental Health Care Providers (higher sources of stigma), there is an opportunity for advocacy because of their strong will to get involved in the program.

- Process:
  Phase 1- Review of available research opportunities
  Phase 2: Stake holder consultations and international research
  Phase 3: Campaign planning (current phase)
  Phase 4: Formal Social Marketing Strategy

- Goals for today:

  Review our research
  Identify how to deploy and sustain a youth social marketing initiative
  Discuss potential roles and responsibilities for the MHCC and program partners
  Identify strategies for success

- Youth Campaign:

  The campaign will focus on three stages: Awareness- Knowledge-Action (Engagement)
  We will need to explore some of the challenges in achieving each of the above stages.

- Currently, there is no quantitative benchmark among Canadian youth to tell us:

  What are the issues that need to be addressed?
  Where are the optimal points on engagement?
  Which initiatives have the broadest and greatest impact?

John also reviewed four international programs that were evaluated from an execution perspective to determine common areas in best practices (refer to PPT presentation).

Questions or Comments

Q: Are there any differences between the international models – in terms of how they organized human power? Who are those people engaged in the campaigns? Are they active participants? Or evangelists?

A: They are active participants. It was driven by series of volunteers in the different markets. The opportunities provided community based involvement.

Q: Segmenting by audiences – do we know if there are significant differences between the various youth audiences?

A: There are different attitudes that run across traditional demographics. Segmentation has been traditional. Scotland took different approach for rural vs. urban markets.

While the identified target audience is 12 -18, many questioned this and wondered why we are not targeting 18 to 24 year olds as well. It was explained that the 12-18 group was identified by mental health professionals as a key priority.

Breakout Session 1 – What criteria should we apply towards selecting regional pilot programs?

Participants were divided into groups to discuss the above issue and provide their comments. The following is a summary of the common elements that were identified from the presentations.

- For the most part, projects should be tied to recovery(holistic approach)
- An open RFI (Request for Interest) process should be implemented that invites proposals from the widest possible range of organizations
- Pilots should be youth driven through every stage, but allow for participation by experienced professionals to help provide guidance and mentorship
- Projects need to be assessed so that they “do no harm”
- Pilots could include a combination of new and existing programs as well person-to-person and/or on line projects
- Do not miss grassroots(small programs) and make pilot funding accessible for all groups by building in support networks for these small, less sophisticated groups to develop their project proposals
- Ensure that those organizations asking for pilot funding have the organizational capacity to deliver the project
- Projects should have the capability of being transferable (replicable) in other environments
- Pilot organizers need to be willing to share data/best practices with the MHCC
- Needs to be a built-in capacity to improve and modify the program throughout the pilot execution process so that the end result is a project that works to its maximum potential
- The MHCC should be responsible for evaluating the pilot projects.

Breakout Session 2 – Where are the optimal entry points and approaches for engaging youth? How do we recruit youth champions? Same format as Breakout 1

Summary of Common Elements

- Need to pull together youth to ask how they want to be engaged. This would include the creation of on going reference groups to provide constant feedback on various aspects of the campaign.
- Need to acknowledge that youth are the experts in the area and that their input is critical to the success of any campaign
- In terms of engaging youth, online presence is of critical importance because this is where "they reside". This includes blogs, Facebook, MySpace, Twitter and other social media tools. Just as important is the use of text messaging and other mobile technologies to communicate with youth on a frequent basis.
- The issue needs to be seen as a social justice issue to get real take-up from youth.
- Schools serve as an optimal touch point (teachers, counselors, coaches, youth champions, etc)
- Can't ignore parents who are a link to the kids; for some kids it's the parents who are the strongest link.

Breakout Session 3 – How will we engage consumers (particularly young adults) in a coordinated, consistent national manner?

Summary of Common Elements

- One of the biggest issues was identifying what is out there as far as consumer groups that can be tapped into for their expertise / engagement.
- Overall, there is a recognition that engaging consumers will take time and patience. Use youth and their voice to get the message out, be realistic about their capacity to deliver. Also need to keep in mind not to overload kids and take into consideration the time they are willing to donate.
- Other issues to consider include 'what does meaningful engagement look like?" and "are views of consumers and/or the general public different?"
- Focus on disseminating good news as a means of encouraging other consumers to come forward with their own experiences
- The process by which consumers are engaged is just as important as outcome
- We need to engage advocates/influencers as a means of reaching consumers
- Will need to rely on local people to access a community
- Parents/siblings also need to be considered a primary audience for reaching and influencing consumers, as well as providing a "safety net".
- Need to bring the experts (youth) to the table, possibly in a Youth Advisory capacity to provide first-hand expertise on how youth can become engaged
- Schools/teachers were also identified as a primary market for reaching / engaging consumers. Schools are the workplace of youth and will be likely to work as a school-based intervention (school in the broader sense). Schools are also desperate for content and this represents an opportunity. Schools also provide an effective safety net.

Breakout 4 – How will we engage advocates and influencers (e.g. teachers, law enforcement, and faith-based groups) and companies that market to youth?

Summary of Common Elements

- The family should be a primary target. You can't talk about youth without talking about parents and siblings. Siblings are also seen as important because they can be a factor in increasing stigma.
- Need to look at partnerships within local communities (incl. local businesses)
- To access the community, you need key community members on the access teams because they provide the insight and credibility to directly engage advocates / influencers
- Once again, a common theme was expressed to bring the experts (youth, consumers) to the table to provide insight
- Within the school environment, you need to engage parents, teachers and others involved with students (horizontally and vertically). It is strongly believed that school boards will not turn away help to deal with youth with mental illness. However, general health is not on the curriculum and getting mental health recognized at this capacity would be even more difficult. The opportunity is to pursue special programs that meet the need
- Scouts were also viewed as a likely source of influencers
- Need to consider the First Nations, Inuit and Metis People as unique
- Need to establish companies' roles and how they can contribute. Most likely approach is to focus on workplace issues. Has to be the right fit for the right ethical reasons – for example, companies that are aligned with positive values and the MHCC mandate
- Need to focus on moving from cultural awareness to cultural competence to cultural safety, which will emerge once the two other levels are achieved.

General Discussion – How will we measure the success of MHCC and pilot programs?

Discussion revolved around what we will measure, what changes will point to success, and the kinds of programming MHCC should consider, that will more likely lead to overall success.

In terms of what needs to be measured, and how that will be accomplished, participants made the following points:

- There still need to be baseline measurements including both qualitative focus groups and quantitative data
- Individual pilot projects need to be measured by the difference they make in the lives of people with mental health problems and whether their experiences change as a result of a project
- Consumer evaluations must occur over time, with panels or focus groups occurring on a regular basis. This part of the evaluation is not to be confused with program evaluations which will focus on reach, implementation metrics, value for dollar / resources allocated, etc.
- Evaluations can include web-based petitions, to measure if the campaign has impacted youth
- At the present time, two thirds of people don't receive care because of stigma - if that number diminishes it will be one way to measure success
- Need to develop mechanisms to measure a mentally healthy workplace
- Measuring effectiveness means evaluating a change in both attitude and behaviour
- Surveys need to be regional to see how people are affected in their own backyard

- When evaluating success, we need to figure out how to differentiate political correctness versus reality, in terms of attitudinal and behavioural changes. The suggestion was made that this can be indicated using a social desirability bias(1 instrument that can side-step the qualitative testing)
- Research needs to be timely, with information reviewed on a frequent basis to determine change
- Need for a multi stage / multi level evaluation plan
- Use social marketing evaluation: knowledge belief behaviour model (pre and post)
- Measurement will need to be consistent among the various projects. Therefore the MHCC needs to be at the centre of measurement and not expect individual projects to decide on their own how to evaluate their success
- Will need to consider value for dollar

In terms of projects and information that will lead to success, participants raised the following points:

- When choosing projects, MHCC needs to include a focus on reducing self-stigma
- Messaging needs to point to ease of disclosure (and this can be measured)
- Projects need to promote people seeking help sooner
- Messaging will carry a strong element on the health and promotion side
- Don't reinvent the wheel(engage the research people to be creative)
- Participants caution that one of the main difficulties in the world of stigma is that stigma is not linear
- The point was also made that Change in Belief will be achieved through personal stories, so messaging must include contact and personal stories

Participants also pointed to the fact that the health care system is not able to deal properly and in a timely fashion with the people coming for help, but success in the initiative will hopefully result in a drive to get money into the system to support those who come forth with mental illnesses. In addition, given the projects that MHCC advisory committees are now beginning to undertake, we need to ensure that work is not duplicated, and that all committees will work collaboratively with each other and with the Anti-stigma / Anti-discrimination Initiative team

Closing Remarks / Next Steps

Micheal closed out the meeting by stating that the MHCC will ensure we are working collaboratively so that we get the most out of our resources and are not working against each other.

MHCC will be meeting with representatives of the Health care providers sector to allow for their input.

HBS and CEPSM will create a report on their suggested course of action for the campaign and we will share the findings with the persons present at today and yesterday's meetings.

Meeting adjourned at 4:40 p.m.

Mental Health Commission of Canada

Anti-Stigma/Anti-Discrimination Planning Session

Summary of Discussions

December 2, 2008

Present: Ella Amir - CHAIR, Family & Caregivers Advisory Committee; Ian Arnold - CHAIR, Workforce Advisory Committee; Louise Bradley - VP & COO, Regional Mental Health Program AB Health, Edmonton Region; Don Buchanan - Child & Youth Mental Health CHEO; Elaine Campbell - Canadian Association of Social Workers NS; Romie Christie - Project Manager, Anti-Stigma Campaign MHCC; Theresa Claxton - National Consumer Council, CMHA; Karen Cohen - Executive Director, Canadian Psychological Association; Bernie Colterman - Director, CEPSM; Christine Davis - Canadian Federation of Mental Health Nurses; Ron Gravel - Statistics Canada, Mental Health Portfolio; Don Hewson - President & CEO HBS Marketing; Francine Lemire - College of Family Physicians of Canada, Service Systems Advisory Committee; Jim Mintz - Director, CEPSM; John Petitti - VP Strategic Planning and Social marketing practice leader, HBS; Laura Panteluk - College of Registered Psychiatric Nurses of Manitoba; Mike Pietrus - Director, Anti-Stigma Campaign MHCC; Maura Ricketts - Director, Office for Public Health Canadian Medical Association; Heather Stuart - Senior Consultant, Anti-Stigma Campaign MHCC; Chris Summerville - Schizophrenia Society of Canada, MHCC Board Member; Denise Taylor - Director, Aboriginal Health BC Interior; Patrick White - Past President Canadian Psychiatric Association, Regional Program Director Mental Health, AB Health Edmonton Region; Lorne Zon - CEO, Canadian Mental Health Association, Ontario.

Welcoming Comments and Introductions

Meeting started at 9:32 AM

Micheal Pietrus opened the meeting with the following comments:

- The MHCC has been tasked with a 10 year anti-stigma campaign. Undertaking a broad based campaign is not the best route to go. In first year, MHCC has chosen two audiences as targets; Youth and Health Care Professionals

- Consumers have told us when they deal with the front line they experience significant stigma. We've brought you together because you have the knowledge that can help us

- Developing pilot projects which are scalable will be one of the MHCC's priorities. The Commission has conducted initial research and created an operational plan. The meeting in September with national stakeholders was to help establish guiding principles and goals. HBS and Centre of Excellence for Public Sector Marketing (CEPSM) were retained to help the MHCC achieve its goals

- Through this workshop, the MHCC is looking for feedback, comments, and ideas on how to work collaboratively on moving this initiative forward

Review of Process and Expected Outcomes

The goal of the session will be to validate ideas through the professionals in the field. HBS and CEPSM will lead the session. Participants were asked to express their open and honest opinion on all topics covered during the meeting.

Guest Speaker-Gillian Mulvale

Gillian shared a personal story of her battle with post-partum depression and her positive and negative experiences with health care professionals.

She spoke on how stigma coming from health care professionals can hurt but also how they have the power to help. “It’s about how you treat people; there is a story behind each person and behind the labels. People have to assume there is a story, and ask - What can I contribute to help this person?”

Presentation of Research and Strategic Directions

John Petitti presented *Building Advocacy within the Health and Mental Health Care Professions*. (Please refer to Power Point Presentation). Selected comments include:

- Health care professionals have the highest opportunity to make a change in stigma and discrimination in mental health field.

- We have the opportunity to engage health and mental health care professionals as the leading champions for the elimination of stigma, discrimination, and for positive change in health care service delivery

- Barriers include:

    - The System: Driving change in the health care system
    - The Culture: Build consensus around a strategy to address both public and professional stigma and discrimination.
    - The Frustration: People have lost faith-we need to restore faith.

- There are some best practices from comparable social marketing campaigns that may be applied to the Canadian solution. They include:

    - Measurement: Clear consensus across all associations and stakeholder groups.
    - National Consumer Survey: Help us prioritize the issue
    - National Health Professions Survey: Understanding of the health care environment- understand the stigma within and launch an advocacy campaign
    - Qualitative Research: A series of focus groups with health care professionals to explore advocacy, strategies, messages and tactics
    - A lead organization takes the role of the central catalyst by consulting with stakeholders to develop a national strategy to address mental health illness, assembling best practices library on advocacy and anti-stigma and ensuring organized and systematic engagement of health care providers

Opportunities Stakeholder Action

- Ensuring issues of stigma and discrimination are addressed effectively in university and college training
- Tapping into existing communications and education channels
- Draw insights from knowledge transfer researchers who focus on de-biasing health care decision making
- Getting the regulatory bodies and the unions engaged to gain broadest access to regulated and unregulated health care workers
- Developing peer-based, grassroots advocacy programs
- Involve key stakeholder professional associations in the process

Consumer Involvement:

- Conduct national online survey of consumer advocacy and support groups (identify initiatives currently underway)
- Seek guidance on developing a frame work

Training:

- Take advantage of existing resources
- Conduct quarterly training webinars on media engagement and advocacy strategies
- Create an online toolkit of resources for distribution in media relations, presentations and conferences

Q&A and Discussion

In a conference in Banff, criticism of the MHCC launching a campaign was expressed. HBS noted that "campaign" doesn't necessarily mean advertising; in this case it is a series of local initiatives. It's been noted that moving forward, wording will be carefully considered and efforts will be made to ensure other professionals and associations understand what the MHCC means when they say "campaign". This is the time to be strategic, targeted, and focused, this is a long term project, and you have to commit to a sustained process. (Note: At the September 23rd Consensus Meeting, group decided "Initiative" is a better word to use than "Campaign")

It was stated that evaluation or measures of success will be very important to be able to improve the campaign and ensure it's a worthwhile project. We need to make sure we value what we measure, so that what we measure is in the end what is valued.

Overall, it was felt that success will be a complete and total change in attitude – a pervasive change. The MHCC is the catalyst but it can't do this alone, it will need to be a collaborative effort.

It was noted that one of the priorities should be changing the culture of health care across Canada and that we need to understand what cultural changes are happening within health care and align what we are trying to do within the system. It was also noted that there are different cultures within health care which we need to address. To achieve this, we need to develop a message that resonates with mental health care workers to make them see it's in their interest to set up a positive environment. We also need to ensure that we build cultural safety around the stigma and discrimination campaign.

Further discussion centred on the fact that we need to turn to the educational system to create the next generation of enlightened health care professionals. Many people think mental health is a low stress environment; so they assume anyone can work in this environment. We need to set up a system where Health Care professionals can be empowered. To move away from stigma we need to treat individuals with mental health issues as individuals, not as the problems, themselves. Different mental illnesses have different stigmas; also the kinds of stigma vary depending on the kind of providers.

Finally, it was noted that we need to find people within the health care system who want to make a difference. We need to identify the health care system provider groups who want to be involved in helping make the change.

Breakout Session 1 – How can the different professions and associations involved in mental health work collaboratively on an anti-stigma and anti-discrimination initiative?

Participants were divided into groups to discuss the above issue and provide their comments. The following is a summary of the common elements that were identified from the presentations.

Summary of Common Elements

- Efforts should be made to make use of existing alliances e.g. CCMHI rather than re-inventing the wheel. The MHCC should serve as a centre point for collaborative expertise.
- Need to clearly identify the goals of the collaborative effort and set the tone at the national level through common messages, accreditation standards, etc.
- Need to focus on project-based actions that involve a number of associations which in turn, will add credibility to any project
- Need to focus on education-based pilots that bring multiple stakeholders together
- The MHCC needs to focus both on multi-disciplinary projects that foster cross-collaboration, and also those where the different associations can take on projects that fit their specific membership
- Should be targeting emergency rooms as a good starting point for collaboration as they represent the “front line” where stigma and discrimination is likely to be experienced and also where a number of professional disciplines work together.
- Need variety of stakeholders and consumers involved at all levels
- Need to take a “No blame” approach, and focus on the benefits of a more positive environment towards mental health
- The MHCC should assemble information and data to create a common body of knowledge that mental health professionals can draw upon.

General Discussion on Breakout 1

It was noted that there should be an overall board or committee that sets a high standard of principles and values that are believable and able to be followed

Discussion returned to the fact that the emergency department is the health care system laid bare, when people with mental health issues are being treated like second class citizens; and through our actions, we are confirming the emergency room is only for physical illness. Mental health is not seen as being important enough to have 24/7 care assigned. We need to address compassion in the emergency room.

The issues in the emergency department become exacerbated when the patient cannot make a connection with a family doctor, when the emergency room or walk in clinic are the only source for treatment.

Finally, it was noted that collaboration should be focused with clear roles, otherwise it may spread the responsibility too thin and then nothing will be done.

Breakout Session 2 – How can the professional associations rally their members around advocacy?

Summary of Common Elements

- Educating members is a critical component of any successful advocacy campaign, so efforts need to be focused on creating these types of opportunities
- Efforts should be placed on creating an advocates forum where key common messages are established that are agreed by all associations
- Develop a roster of speakers that can be mobilized for education purposes
- Need to sell the benefits to members such as "you'll be doing your job better", "you'll have better patient satisfaction", "you'll have a better work environment" and "you'll be building a better system and profession"
- Specifically, what can the MHCC do?
    - Develop the collaborative model
    - Provide advocacy tools that associations can adapt to their own environment
    - Hold workshops, demonstrations, forums that help stakeholders advocate effectively
    - Co-ordinate evaluation
    - Provide financial support
    - Create communication and other advocacy tools
    - Help in involving more partners
    - Setting standards, including accreditation standards
    - Communicating the Commissions' objectives

General Discussion on Breakout 2

The role of the MHCC is bringing together professionals from different backgrounds to discuss points of view. By not having common messages it was felt that we miss opportunities to push those messages. Key messages need to be developed with input from different stakeholders; however, each group needs to "own" their messaging. The MHCC should spearhead a working group that develops key messages.

It was noted that while we need to focus on messages to politicians, we also need to look at what we can do on the ground level. We need to do whatever we can within our own organizations/environments.

A question was asked about the role of the Social Marketing team. It was noted that their expertise will be used to spearhead the efforts of the campaign by amalgamating participants' ideas and developing a strategy from which the campaign and projects can be based on.

Breakout Session 3 – How do we identify potential pilot projects for each of the professions and what can we best hope to gain from them?

Summary of Common Elements

- Need to focus on multi-sectorial (interdisciplinary) opportunities where multiple professions can work towards a common, collaborative goal e.g. emergency rooms
- Need to develop both short and long term targets
- Projects should be guided by a Project Advisory Committee representing the various mental health sectors
- Project priorities should be based on common issues, be realistic and feasible from an implementation perspective and be capable of early success
- Sustainability of the work undertaken through projects should be a key factor, so that a legacy is created
- Accreditation standards were viewed as one of the priorities, as well as work site training
- Conducting a survey (across all sectors) was viewed as important for setting baseline information on the problem, barriers and consumer experiences relating to stigma
- Role of the MHCC
  - Administration
  - Leadership
  - Facilitation
  - Organization
  - Logistics
  - Evaluator
  - Objective 3rd party to bring stakeholders together

General Discussion - How will we measure the success of the campaign?

- Need to set benchmarks in all areas (e.g. consumer, profession, workplace) to determine our starting point
- Need to start with the consumers: their overall experience, level of satisfaction on how they were treated and the respect they received. Also, is there a shift in self-stigma?
- Also need to measure success from the health care worker's perspective
  - Overall satisfaction
  - Mentally healthy organization
  - Quality audit
- Evaluation should be tied to specific pilot projects
- Projects should demonstrate value for dollar

It was noted that at some point, infrastructure requirements will need to be addressed in order to deal with the number of new requests for assistance, based on greater response as a result of the campaign.

Closing Remarks/ Next Steps

HBS and CEPSM will create a report on their suggested course of action for the campaign and will share the findings from today's planning session.

Meeting Adjourned @ 4:17 p.m.