

THE MOOD DISORDERS SOCIETY OF CANADA (MDSC)



STIGMA HURTS!

STIGMA AND DISCRIMINATION RESEARCH WORKSHOP

Report of the Proceedings
Prepared by
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Mood Disorders Society of Canada
La Société Pour **Les Troubles de L'Humeur** du Canada

Executive Summary

Stigma and discrimination are widespread and persistent toward people who experience mental illness, their families and caregivers. Stigma causes serious economic, health and social consequences to consumers, patients, families and caregivers as well as to society at large. The experience of stigma, and its resultant discrimination, is a profoundly personal one and best understood by those who have experienced its effects. Although we know of its harmful impact, stigma is currently under-researched in Canada and throughout the world.

As part of its mandate to support those with mental illness and offer leadership in strategies to address mental illness, the Mood Disorders Society of Canada (MDSC) convened a national workshop to explore the issues around stigma and discrimination. The goals of the workshop were:

1. To develop a comprehensive researcher and consumer/family focused research agenda.
2. To develop materials to inform the Mental Health Commission of Canada.
3. To encourage an exchange of ideas and build collaborative research teams and networks.
4. To develop national and international partnerships among funders, researchers and stakeholders.

The workshop brought together approximately 90 individuals representing individuals affected by mental illness, families, caregivers, health care providers, researchers, government, policy makers, and non-profit organizations. They spent two days listening to each other, hearing from individual experts involved in stigma research, and addressing the goals through large and small group structured discussion. Their efforts resulted in a list of sixteen priorities stated in terms of questions that could be used to identify research priorities.



The questions, in order of priority, are:

1. *What are the most effective strategies to reduce stigma and discrimination associated with mental illness and addictions among health and social service providers?*
2. *There are a number of promising consumer-led anti-stigma programs. How effective are these?*
3. *What do mental health (MH) professionals do/not do that consumers experience as stigmatizing and discriminatory?*
4. *What factors increase or decrease stigma for individuals, families, organizations and communities?*
5. *What is needed to help service providers recognize and change their own stigmatizing attitudes and behaviours?*
6. *What is the best way to teach children/youth about mental health (MH) issues using identified promising practices that reduce stigma?*
7. *In which ways do children and youth experience stigma and discrimination?*
8. *What role does the post-secondary educational system and health and professional training play in perpetuating stigma and discrimination or empowering consumers and families? What strategies might be effective in reducing stigma and discrimination with this group?*
9. *What are the necessary elements of effective “contact strategies”?*

- 10.** *What are useful indicators and tools to measure progress in reducing stigma (if we reduced stigma what would the world look like)?*
- 11.** *What is the impact of empathy-centred early interventions to reduce the stigma associated with mental health difficulties?*
- 12.** *What is the impact of existing programs and policies relating to workplace mental health and what are the barriers to implementing workplace policies and programs to assist employees with mental health problems?*
- 13.** *What role does stigma play in the decisions to fund or not fund research for self-help, peer support and similar community services?*
- 14.** *What is the role of worldviews/models of care/language (naming) in perpetuating or reducing stigma?*
- 15.** *What is the relationship between social and self-stigma (internalized stigma)?*
- 16.** *How do we increase, target and best allocate funding to best address stigma and MH literacy – the language that describes mental health and mental illness?*

Participants spent time working with questions 1-9 to identify key action steps for moving forward and addressing the questions. Following broader discussion there was agreement that the following principles and core values should underline all research questions. These were:

- All research questions reflect a recovery model.



- The research questions reflect the age span.
- The research questions reflect the spectrum of illness.
- Care providers and family perspectives are included.
- All research questions use valid and reliable tools or established methods.

Recognizing that this was the first attempt to bring together individuals to discuss the issue of stigma and discrimination, much was accomplished that will lay a foundation for further dialogue. The unique opportunity to gather researchers, families, caregivers, policy makers, government and non-profit organizations, and health care professionals is unprecedented in Canada. The workshop facilitated dialogue among groups that are not generally connected to each other. It allowed networking, a movement toward shared understanding of how stigma and discrimination impacts various stakeholders and the beginning of a plan to systematically address key questions. Participants are looking for continued commitment to sustaining the momentum generated by the workshop. This requires collaboration among groups represented at the workshop, but also others who were unable to attend. It also requires leadership and support at all levels of government in the form of a national approach. The work has just begun.

ACKNOWLEDGEMENTS

MDSC Project Team

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Marg Osborne, *National Board Member, Canadian Mental Health Association*

Dr. Paula Stewart, *Public Health Agency of Canada*

Senator Michael Kirby, *Chair, co-chair of the Standing Senate Committee on Social Affairs, Science and Technology*

Funders

Institute of Neurosciences, Mental Health and Addiction - CIHR

Public Health Agency of Canada

CIHR – Institute of Human Development, Child and Youth Health

CIHR - Institute of Gender and Health

B.C. Mental Health and Addictions Research Network



INTRODUCTION

The experience of stigma is not unique to those suffering from mental illnesses, their families and caregivers. However, stigma and discrimination are widespread and persistent toward them. Stigma causes serious economic, health and social consequences to consumers, patients, families and caregivers as well as to society at large. The experience of stigma, and its resultant discrimination, is a profoundly personal one and best understood by those who have experienced its effects. Although we know of its harmful impact, stigma is currently under-researched in Canada and throughout the world.

In light of the need to address stigma and mental illness, the Mood Disorders Society of Canada (MDSC) prepared a proposal, met with funders, and conceived a plan to bring together individuals who experience stigma and those who want to work to address it. Following several months of planning, the workshop took place on October 2, 3, & 4, 2006 in Ottawa, Ontario¹. This report describes the workshop format, summarizes the plenary/panel presentations, and documents the large and small group discussions that occurred.

The goals of the workshop were:

- To develop a comprehensive researcher and consumer/family focused research agenda.
- To develop materials to inform the Mental Health Commission of Canada.
- To encourage an exchange of ideas and build collaborative research teams and networks.
- To develop national and international partnerships among funders, researchers and stakeholders.

¹ A full summary of the workshop goals, background readings and orientation materials are posted on the MDSC website at <http://www.mooddisorderscanada.ca/Stigma/index.htm>

Approximately 90 individuals from various sectors attended. Each participant was asked to prepare for the workshop and was provided educational materials in advance of the workshop. Participants included mental health consumer and family caregiver leaders, clinicians, non-governmental agencies, politicians, and researchers².

Workshop Format

The workshop planning team, led by MDSC, developed the agenda and format, invited speakers, secured funding, established a scholarship program to facilitate consumer and family involvement, identified potential participants, issued invitations, prepared background materials, and arranged on-site logistics. A stigma and discrimination website resource was created to orient participants including related background readings, presentations and resources.

<http://www.mooddisorderscanada.ca/Stigma/index.htm>.

In keeping with the workshop goals, the two-day event offered opportunities to hear from a variety of individuals through plenary and panel sessions and included several opportunities for structured small group discussion and exchange of ideas. Informal networking occurred throughout the workshop.

The event opened with welcoming remarks by Phil Upshall, MDSC's Executive Director. Following dinner, Bernard McNair delivered the keynote address entitled "*Just put on some lippy love and that will make you feel better*"³. He described Australia's efforts to address and improve the mental health of its residents, in particular through "*beyondblue – The National Depression Initiative*". This initiative focuses largely on the workplace and tries to change attitudes

² A delegate list and brief biographies are available on the MDSC website at http://www.mooddisorderscanada.ca/Stigma/stigma_delegate_contactlist.htm

³ A copy of the presentation is available at <http://www.mooddisorderscanada.ca/Stigma/index.htm>



about depression among workers. The program uses media and youth to increase public awareness about mental illness and encourage support of those who come forward to seek help. A key element of *beyondblue* as it looks at research is to ensure that the voices of consumers and carers are heard and listened to. Dr. McNair's message was consistent with the philosophy of this workshop, which is the inclusion of consumers in any research that is proposed.

The evening continued with a panel presentation designed to describe how stigma is manifested within various sectors such as:

- The professional community – doctors, health caregivers
- The research/researcher community
- The legal community
- The consumer/family community

The panel was moderated by Senator Michael Kirby (*Liberal Senator for South Shore Nova Scotia and Chair of the Standing Senate Committee on Social Affairs, Science and Technology*). Senator Kirby spoke about the report of the **Standing Senate Committee on Social Affairs, Science and Technology** on mental illness. The report is entitled *Out of the Shadows at Last*⁴ to reflect the long history of hiding mental illness because of the stigma associated with it. The Mental Health Commission is critical to ensuring that mental illness does not return “to the shadows”, and the Senator is very optimistic that the Commission will be established.

Senator Kirby remarked that committee members were struck by their own personal experiences regarding mental illness. As they shared their stories, it

⁴ The report *OUT OF THE SHADOWS AT LAST: Transforming Mental Health, Mental Illness and Addiction Services in Canada*, The Standing Senate Committee on Social Affairs, Science and Technology can be found on-line at <http://www.parl.gc.ca/39/1/parlbus/commbus/senate/com-e/soci-e/rep-e/rep02may06-e.htm>

became apparent that all had a loved one with mental health problems of some sort and all had had negative experiences with the mental health care system. They concluded that when each of eleven people reports negative experiences, there is something fundamentally wrong with the system itself. Committee members had previously been open with each other about their physical health conditions or those of family, but prior to this discussion, had kept the mental health conditions of loved ones to themselves.

The personal stories presented to the committee convinced them that, in many cases, the stigma of the illness is worse than the illness itself. In the course of their work on this issue, committee members were also surprised to discover that ironically and sadly, stigma is common among mental health professionals, just as it is in the general public.

Senator Kirby indicated that background information is needed to get the Commission “up and running”. A background paper on knowledge translation will be released shortly, and the report on stigma arising from this workshop will be welcomed by the Committee. He emphasized the crucial importance of the fight against stigma.

Dr. Paula Stewart, (Title) Public Health Agency of Canada, spoke about stigma in the mental health professions. She shared a personal story about her daughter’s struggle with a serious anxiety disorder and their family’s experience with the health care system. She emphasized the importance of the personal stories of people with mental illness and the need for supportive, nurturing networks. Even supportive family members often do not fully understand the issues of mental illness; going through a mental illness with someone can open their minds.



Dr. Stewart said that the most important thing physicians need to learn is that *you do not treat someone with a mental illness, you walk with them. You do not “fix” people with mental illness – they live with it and you journey with them.* This can be difficult for physicians, who are trained to measure and fix problems.

Physicians have to believe what a person with mental illness is saying about his or her experience because, unlike other illnesses, there is no objective proof. Medical training does not prepare physicians to work effectively with mental health problems. Physicians need to view persons with mental illness as whole people and find out what they can do to walk with them in a way that honours them. She has told health care providers that “opening your arms to people is profoundly moving”.

Dr. Rémi Quirion, Canadian Institutes for Health Research, Institute of Neurosciences, Mental Health and Addictions, remarked that we could learn a great deal about reducing stigma from Australia, suggesting there is no point “reinventing the wheel” here. He also noted that groups representing consumers and families with a wide range of mental and neurological disorders work with the Institute and provide important information that grounds its research initiatives. The Institute needs the help and support of everyone at the conference. Stigma is still the daily lot of Canadians with mental illness and we need an action-driven agenda at all levels, from school playgrounds to Parliament Hill. We need to focus not only on recovery but also, in some cases, on cures. *“Thinking about cures makes you dream a little bigger”.*

Dr. Quirion talked about stigma and psychiatry. Mental illness is very complex and the brain represents the last frontier in medicine. We still do not understand all of the impacts of genetics, environment and culture. We must be able to convince our brightest young people to choose a career in mental health, whether in research or in psychiatry. He noted that psychiatry itself is

stigmatized as a medical choice – often the brightest young minds will choose specialties with more glamorous profiles. He suggested that perhaps psychiatry should be under the umbrella of neurology, to keep all brain diseases together.

Funding for research on mental illness and issues like stigma is inadequate in Canada and worldwide compared to the burden of disease, even at the basic neuroscience research level. This may be because it is difficult to study the brain and also perhaps because of inadequate support from the public in terms of donations. Over \$50 million is provided each year by Canadians for cancer research and for heart and stroke research, compared to perhaps \$5 million for all brain research.

We need to learn from our colleagues in cancer research about combating stigma and building support through advocacy. We need more champions like Michael Wilson, including sports figures, artists and politicians. They are most effective in convincing government to fund research. Supporting effective research to fight stigma is part of the Institute's strategic plan, but major shifts in public attitude are required before individuals with mental illness can talk about it as easily as surviving a heart attack or cancer.

The Honourable Justice Ted F. Ormston, Ontario Court of Justice – Toronto Region, has been a judge for 20 years and was the first judge of a Canadian Mental Health Court. He remarked that the public has made judges the gatekeepers of Canada's largest mental institution – the prison system. He told conference participants that his instruction to other judges involved in the Mental Health Court is *“close the book and open your heart; empathy is the key in dealing with mental illness”*.



Judge Ormston noted that stigma includes perceptions of dangerousness and criminality. Many Aboriginal people are in prison for example, because of Fetal Alcohol Syndrome, which is actually a brain disorder. Police know a lot about stigma and must be a part of whatever we do to combat stigma. They are the often the first responders in mental health crises. When someone is threatening to burn down his house, or a teen is threatening to jump off a bridge, people call the police. The police are familiar with systemic stigma. There is often nowhere other than jail or the emergency room where they can bring people suffering mental health crises, but there is a shortage of hospital beds and people cannot be held for long in jails and so they are soon back on the street. We need more options. Additionally, doctors are often unable to share information with police or the courts, which can be an obstruction.

He suggested that what is really missing in these cases is empathy. We need to teach children about empathy, civil behaviour and tolerance from an early age; this will eliminate a lot of criminal behaviour. Stigma will be reduced the same way it is created. For example, children taught early about the link between smoking and cancer pressure their parents to quit. Rigorous, sound research about what works to reduce stigma is needed. The Roots of Empathy program, which brings young infants into classrooms to teach empathy to children has been evaluated and shown to reduce bullying and promote social inclusion. Stigma implies a lack of empathy. Society as a whole needs more empathy; this will reduce crime and improve society overall.

Bernard McNair, Executive Director, Healthcall Consulting Services, Consultant – Mental Health at Work and beyondblue, the National Depression Initiative, Australia, discussed the role of consumers and family members regarding stigma. A study published six weeks ago at the University of

Sydney indicates that bullying has three times as much impact as sexual abuse on children because it is so common.

He described an example of an anti-stigma initiative in Australia: Stigma Watch, implemented by a group called Sane Australia. Sane Australia is a mental health charity that operates a website on which people can record examples of stigma they have seen in various places. About 45% of complaints relate to the print media and about 15% to television. The majority of complaints are sent in by consumers and carers. For example Sane Australia was successful in pressuring a restaurant to change the labelling of items on its menu (psycho tacos and asylum salad) and taking a magazine to the Human Rights Body and the Press Council for an article that described and compared the best methods of suicide. Although initially dismissive it was forced to issue a public apology. These examples show that a lot of work is still needed with regard to stigma and initiatives like Stigma Watch can have a significant impact.

The evening concluded with a question period, where participants raised a variety of issues for discussion, including: gender, culture, terminology, myths, discrimination, and addictions in relation to mental illness. A transcript of the questions and panel responses is included in Appendix (B).

The first full day of the workshop opened with a welcome by Phil Upshall and introduction to the workshop goals by Neasa Martin, Project Lead. The importance of coming together as informed individuals and not as advocates for a particular sector was emphasized. This was followed by **Dr. Patrick Corrigan** who delivered the day's keynote presentation, entitled "*Don't Call Me Nuts: Beating the Stigma of Mental Illness*"⁵. Dr. Corrigan began by offering definitions and examples of stigma. He noted how the media maintains stigma and talked

⁵ A copy of Dr. Corrigan's presentation is available on the MDSC website at http://www.mooddisorderscanada.ca/Stigma/stigma_beattheillness.htm



about The Chicago Consortium for Stigma Research. The main focus of his presentation was combating stigma. The three major approaches are:

1. Education
2. Protest
3. Contact

Education can dispel commonly held myths about mental illness. Protest involves challenging commonly held images of stigma. Through Contact, we can put a human face on mental illness as famous and not-so-famous individuals go public with their experiences of mental illness. Contact appears to benefit both the person with mental illness and those hearing the message by mitigating the stereotypes and the negative attitudes that go with them. Contact does however have the potential for increased discrimination/stigma to self, family and friends.

Dr. Barbara Everett presented a paper entitled *“Stigma: The Hidden Killer: MDSC Background Paper and Literature Review”*⁶, which had been provided to participants as background prior to the workshop. The presentation highlighted key aspects of the report and offered guidance on potential areas for research initiatives. She noted that the media, the general public and health professionals all contribute in their way to stigma. She offered several recommendations for international research on stigma, noting the importance of involving those who are directly affected. Some of the emerging best practices in anti-stigma campaigns include:

- Dedicated senior government leadership willing to champion the project
- Adequate and sustained funding and interventions over the long term
- Well-defined goals

⁶ A copy of Dr. Everett's literature review and presentation is available on the MDSC website at http://www.mooddisorderscanada.ca/Stigma/stigma_hiddenkiller_present.htm

- Comprehensive approach
- Ensuring evaluation is planned for from the beginning
- Communication of progress and results broadly

Both presentations were given to stimulate and inspire participants for the task of identifying research priorities.

The balance of the workshop was focused on input and responses from the group during large and small group discussions. The small group tasks were as follows:

Task One: Brainstorm research priorities in small groups, record all, then discuss, clarify and consolidate priorities into distinct items (no duplication). Create a list of no more than 10 items (reduce to this if necessary by an agreed upon group process).

Task Two: Prioritize the list of 10 priorities (by a method the group agrees to) and write research questions for the top five priorities.

Task Three: Submit the top two research questions to the Facilitator

Participants were divided into eight small groups and encouraged to assign roles of recorder, reporter and internal facilitator (to keep on time and on task).

The initial brainstorming session produced close to 150 priorities among the eight groups and covered a range of themes and issue areas, including but not limited to the following:

- Youth
- Medical Community and first contact



- Media
- Funding
- Multicultural / Diverse Communities
- Genetic Link of Mental Illness and how it applies to stigma
- Effects of stigma

One group approached the task by first identifying principles that should be used in developing research questions. These included:

- We “are” and we “must” work from the same definition of stigma
- Stigma research must be inclusive across the age span
- Must understand and be aware of the connections between Stigma and Discrimination
- Research should focus on opportunities that allow for quick wins and outcomes
- It must be inclusive across the continuum (e.g. community, LTC, schools, acute care etc.)
- Research methods should be inclusive of both qualitative and quantitative and should involve a variety of creative approaches (e.g. arts, narrative...)
- Mental health/stigma should be measured and researched equally as physical disabilities/conditions

The group also noted the importance of keeping in mind several issues during the process of developing research priorities:

- The distinction between self stigma and public discrimination
- Mental illness affects the body, mind and spirit

They also noted that consumers must make a difference in the process of setting research priorities, and the importance of people telling their own stories and partnering on the next steps in developing a research agenda.

A second group identified some values/principles that should underlie all questions. These were:

- All research questions reflect a recovery model.
- The questions reflect the age span.
- The questions reflect the spectrum of illness.
- Care providers and family perspectives are included.
- All questions use valid and reliable tools or established methods.

Groups discussed and consolidated items, clarified where required and submitted two research questions for discussion within the large group. The sixteen research questions submitted by the groups were:

1. *What are the most effective strategies to reduce stigma and discrimination associated with mental illness and addictions among health and social service providers?*
2. *There are a number of promising consumer-led anti-stigma programs. How effective are these?*
3. *What do mental health (MH) professionals do/not do that consumers experience as stigmatizing and discriminatory?*
4. *What factors increase or decrease stigma for individuals, families, organizations and communities?*
5. *What is needed to help service providers recognize and change their own stigmatizing attitudes and behaviours?*
6. *What is the best way to teach children/youth about mental health (MH) issues using identified promising practices that reduce stigma?*



7. *In which ways do children and youth experience stigma and discrimination?*
8. *What role does the post-secondary educational system and health and professional training play in perpetuating stigma and discrimination or empowering consumers and families? What strategies might be effective in reducing stigma and discrimination with this group?*
9. *What are the necessary elements of effective “contact strategies”?*
10. *What are useful indicators and tools to measure progress in reducing stigma (if we reduced stigma what would the world look like)?*
11. *What is the impact of empathy-centred early interventions to reduce the stigma associated with mental health difficulties?*
12. *What is the impact of existing programs and policies relating to workplace mental health and what are the barriers to implementing workplace policies and programs to assist employees with mental health problems?*
13. *What role does stigma play in the decisions to fund or not fund research for self-help, peer support and similar community services?*
14. *What is the role of worldviews/models of care/language (naming) in perpetuating or reducing stigma?*
15. *What is the relationship between social and self-stigma (internalized stigma)?*

16. How do we increase, target and best allocate funding to best address stigma and MH literacy – the language that describes mental health and mental illness?

Considerable discussion ensued following the posting of the priorities. The essence of the discussion is summarized below:

The following concerns with the process were expressed:

- There is no mention of seniors, although there are two questions relating to children and youth (the focus on youth was defended on the grounds that the best way to reduce stigma is by focusing on educating young people).
- The questions have little relevance to advocacy/policy.
- Different cultural/linguistic groups need to be considered.
- There should be more focus on addictions, which has been dropped into the shadows because of stigma. People with addictions have to be at the table; their needs are not the same, but they are just as real.
- Some questions seem to be redundant; how will these be reconciled?
- The way questions are structured will make a difference in how the issue will be examined – “how” versus “what” questions, for example.
- Some questions also appear to be more doable than others.
- There was some concern about the process of selecting priorities by group voting, particularly since there had already been a lot of content lost from the individual group work.

All participants agreed that they would like the report to include a preamble outlining core values, principles and issues of marginalization.



One participant noted that getting informed consensus from small groups was a tough and draining process. There appear to be four themes emerging, but the participant urged caution in the selection process as there are also other themes that are not listed, including diversity. The four themes are:

- Youth – How do we work with them? What do we do with them?
- Medical/health care/frontline worker group – How they are educated and interact with consumers?
- Funding/financing – Where the money comes from? How is it allocated? Does it work?
- There are many ways of attacking the problem of stigma – how do we evaluate and quantify these?

Another participant asked about which funders would be receiving the report. On behalf of the Schizophrenia Society, the participant offered to collaborate with others in the group who would also be prepared to provide some funding. The group was told that the report is going to CIHR, although it is great that people have identified a desire to collaborate.

Dr. Quirion told the participants that they had worked very hard to come up with a list of priorities. As the funder, the job of CIHR is to persuade the government to set up the Mental Health Commission and one of its roles will be research. If that does not happen, there are other funders. What we have to do now is prioritize and focus. Participants need to think about a few quick wins. If the Commission is not established for a couple of years, some quick wins would help to convince the federal government to move forward. He asked Bernard McNair to comment on the process from his experience: Are we going the right way?

Bernard McNair responded that there are sixteen good ideas, but the group needs to bring them down to a half-dozen that are doable; these could be used to persuade the government to form the Commission and could influence policy. The group needs to identify the half-dozen that could make a difference. These are not necessarily the most pressing research questions, but are those that could lead to some real change, some policy change in government and that would have some real impact on consumers and carers. He suggested that people take a vote on the top half-dozen to bring forward now and that these priorities may change over time.

Before voting, the group adopted the following key principles for to guide the selection of priorities:

- Select on the potential for a “Quick win”
- Select on the potential for greatest impact on consumers and carers

The group also agreed that each priority will address issues across the age span where relevant, to ensure inclusion of seniors.

Each participant received seven coloured adhesive dots to use in voting for their individual priorities. They were instructed to use all dots and not place more than 3 dots on any single item. The following is the prioritized list of research questions:

1. What are the most effective strategies to reduce stigma and discrimination associated with mental illness and addictions among health and social service providers? **52 votes**



2. There are a number of promising consumer-led anti-stigma programs.
How effective are these? **49 votes**
3. What do mental health professionals do/not do that consumers experience as stigmatizing and discriminatory? **46 votes**
4. What factors increase or decrease stigma for individuals, families, organizations and communities? **45 votes**
5. What is needed to help service providers recognize and change their own stigmatizing attitudes and behaviours? **44 votes**
6. What is the best way to teach children/youth about MH issues using identified promising practices that reduce stigma? **42 votes**
7. In which ways do children and youth experience stigma and discrimination? **38 votes**
8. What role does the post-secondary educational system and health and professional training play in perpetuating stigma and discrimination or empowering consumers and families? What strategies might be effective in reducing stigma and discrimination with this group? **38 votes**
9. What are the necessary elements of effective “contact strategies”? **38 votes**
10. What are useful indicators and tools to measure progress in reducing stigma (if we reduced stigma what would the world look like? **34 votes**

- 11.** What is the impact of empathy-centred early interventions to reduce the stigma associated with mental health difficulties? **32 votes**

- 12.** What is the impact of existing programs and policies relating to workplace mental health and what are the barriers to implementing workplaces policies and program to assist employees with mental health problems? **27 votes**

- 13.** What role does stigma play in the decisions to fund or not fund research for self-help, peer support and similar community services? **24 votes**

- 14.** What is the role of worldviews/models of care/language (naming) in perpetuating or reducing stigma? **12 votes**

- 15.** What is the relationship between social and self-stigma (internalized stigma)? **11 votes**

- 16.** How do we increase, target and best allocate funding to best address stigma and MH literacy – the language that describes mental health and mental illness? **5 votes**

The day ended with an acknowledgement of the tremendous productivity and passion that the group brought to the proceedings. Participants were encouraged to reflect on the outcomes of the day and return the next day ready to begin the process of action planning in relation to the top eight priorities.

The second day of the Workshop began with a brief summary of accomplishments on Day 1 – the identification of priorities offered by participants, the open discussion of issues delegates felt were important, and the opportunity to hear the perspectives of other participants.



The purpose of the second day was to take the priorities and develop preliminary action plans for them by responding to the following questions:

- Who are the likely partners?
- What is the role and responsibilities of each partner?
- Who are the likely funders?
- What are the initial steps required to move this research forward?
- What are the cautions that must be kept in mind in turning this research question into a research plan?

The facilitator indicated that, given the size of the group, the first eight priorities could be tackled. Since priorities seven, eight and nine were tied in terms of votes, priority nine was added to the mix. Priorities five and eight were viewed by the group as somewhat related, so one discussion group took on both priorities (five and eight) together. Another group decided to address priorities six and seven, given their perceived similarity.

Eight small groups were established for action planning, each with one or two priorities. Groups were requested to record their responses to the above questions and submit their notes for this report. *The notes from Group 4 are missing.* All other group responses are included below:

Research Question/Priority #1

- **What are the most effective strategies to reduce stigma and discrimination associated with mental illness and addictions across the age span among health and social service providers?**

LIKELY PARTNERS

- Police forces (federal/municipal/provincial) – largest providers
- Psychiatrists
- Nurses, general practitioners, occupational therapists, social workers
- Centre of Addictions and Mental Health
- Rehabilitation workers
- Non governmental organizations – community
- Community mental health workers – Canadian Mental Health Association
Hospitals
- Native Mental Health
- Universities and educational facilities
- Consumer organizations
- Cultural/diversity/gender
- Income support/maintenance
- International links
- Research organizations – participatory/CIHR
- Media
- Government – Federal/Provincial/Territorial
- Canadian Mental Health Commission

ROLES AND RESPONSIBILITIES

What needs to be done to do our research project?

- Advisory board with key stakeholders that is...
 - Not involved day to day
 - Provides overall direction
 - Key issues
 - Collaboration
 - Money
 - Secondary analysis



- Large groups (30-40) people
- Meets every other month
- Annual input conference that is...
 - Even larger group (100-150)
- Sub-committees...
 - Research team having a principal (conducts research, drafts proposal) and co-investigators (community partners)
 - Media/PR/Communications (dissemination; connects to NGOs/other partners)
 - Policy Committee (analyze research finding in relation to current policy)

Issues/Additional Information

- ▶ All stakeholders to annual meeting,
- ▶ Advisory committee must include consumer and family representatives, e.g. NGO – make sure that research is promoted within networks and that issue is highlighted and “marketed”.
- ▶ How do we “sell” this piece of research to those who would oppose it?
- ▶ Engage with key stakeholder groups such as professionals colleges to get them on board.
- ▶ Can the involvement of some groups be “self-defeating”?
- ▶ Need to involve those groups who are prepared to put their reputation on the line and help identify viable solutions (quick wins).
- ▶ Professional associations already have some relevant guidelines. Perhaps an opening to gain acceptance for research results.
- ▶ “Quick win” could involve “sympathetic” groups and then move out to longer-term engagements with others.
- ▶ This question focuses on what works. Most stigma and discrimination originates among non-specialist healthcare providers.

In light of the above, keep in mind the following...

- Collaborate.
- Look for quick wins.
- Look at literature.
- Caution: How to engage with and get buy-in from those groups where stigma & discrimination is prevalent?
- Quick wins work with those who are willing to come to the table.
- Need to involve those affected by research from the outset.
- Need to look at individual level/association policy in identifying strategies.
- Way question is formulated should encourage partnerships.
- Emphasize positive.

LIKELY FUNDERS

- Social Sciences and Humanities Research Council
- CIHR – INMHA and other institutes
- Corporate (Pharma, banks, Petro Canada)
- Regional/provincial health authorities
- Professional colleges/associations
- Research foundations (Trillium Foundation, those linked to professional associations and nursing directorate)
- Health Ministries/Health Canada
- NGOS – e.g. Schizophrenia Society

INITIAL STEPS

- Start with Community Champions to advocate for this research.
- Need initial developmental funds.
- Endorsement from this group (needs to lead to someone claiming “ownership”)



- Action Committee to: martial developmental funds; refine research question; orient to achieving quick win; point to what further research would then need to be done

CAUTIONS

- Avoid pointing fingers
- Be open/positive

Research Question/Priority #2

- **There are a number of promising consumer-led anti-stigma programs. How effective are these?**

Methodology needs to evaluate existing programs including complete age span as well as diverse population. What are the existing programs?

FIRST ACTIVITY

Define consumer-led program, including “What is consumer led?”

LIKELY PARTNERS

- Neutral research agency
- Leader – National Network for Mental Health
- Mood Disorders Society of Canada
- Canadian Coalition of Alternative Mental Health Resources
- Canadian Coalition for Seniors Mental Health
- Canadian Alliance for Mental Illness and Mental Health
- National Youth Organizations

POSSIBLE FUNDERS

- Office of Disability Issues
- Canadian Institute of Health Research
- Pharmaceutical Companies
- Imagine Canada

INITIAL STEPS

1. Establish steering group National Network for Mental Health
2. Steering group to develop proposal (NNMH)
3. Inventory of existing groups
4. Review existing literature

CAUTIONS

- Huge project – should be started in one area/one province
- May miss groups that are not connected to national groups
- National Network for Mental Health presently developing list

Research Question Priority #3

- **What do MH professionals do/not do that consumers experience as stigmatizing and discriminatory?**

WHO ARE MH PROFESSIONALS?

- Mental health "professionals" – general practitioners, family practitioners, registered nurses, social workers, community home workers, psychologists, psychiatrists, helpers, peer counsellors/supporters, etc.
- People who are "certified"?
- Target group?



LIKELY PARTNERS

- Consumers
- Family members
- International (US, Australia)
- NMHA
- National/provincial consumer organizations
- Self help groups
- Innovation, Policy and Science
- Health Authorities
- “Seniors” Advocates
- Royal Canadian Legions
- Private practitioners
- Professional Licensing Bodies
- Ombudsman
- PT Councils/advocates/researchers

ROLES AND RESPONSIBILITIES

CONSUMERS

- Part of research team,
- Fully involved beginning to end (set question, data collection/analysis, dissemination and reporting, participants)
- Principle – consumers self-identify,
- Direct input from consumers, not through a third party,
- Want a range of consumer voices from mild to severe.

Methods Questions

- Is web-based data collection ok?
- What about consumer literature?

- Is telephone data collection ok?
- How do we find consumers who do not currently have a voice – idea – include street agencies, senior centres as partners

RESEARCHERS

- Honour the consumer voice
- Find the range of consumers across the life span, range of illness experience, The Silent Voice
- Make sure “methodology” is sound
- Ensure use of participatory action research.
- Literature review
- Find the money including money to pay consumers.

LIKELY FUNDERS

- Social Sciences and Humanities Research Council,
- Pharmaceutical Companies (ethics??)
- Public Health Agency
- Rotary clubs
- Trillium Foundation
- Governments
- National Research Council
- Foundations
- Non governmental organizations as the Schizophrenia Society of Canada
- Universities

INITIAL STEPS

- Establish ourselves as a research team.
- Take a project forward – ideally Mental Health Commission is in place, or take it to funders/others for support.



- Be champions – lobby for support.
- Determine status of Kirby report.
- Write proposal/define methods.
- Find money.
- Do it!!

CAUTIONS

- Could try to do too much/cover too much ground.
- Consumer voice has to remain “pure: - do member checking etc
- Establish outside parameters i.e. across life span; include children; geography.
- Adequate funding necessary.
- Analysis of previous consumer voice reports?
- Time and energy needed.
- Wording of question might be offensive to professional.

Research Questions/Priorities # 6 & 7

- **What is the best way to teach children/youth about MH issues using identified promising practices that reduce stigma?**
- **In which ways do children and youth experience stigma and discrimination?**

Next Steps

1. Systematic review (state of science/review): what is the effectiveness of anti-stigma strategies for children and youth? Identify gaps and strengths.
2. Identify/implement/evaluate promising practices in Canadian context.

LIKELY PARTNERS

At individual research project level/research program level

- Kids
- Consumers
- Educators
- Family
- Police
- Child welfare professionals
- Health professionals
- Justice/courts/policy makers related to children (even Arts community as needed)
- Canadian Mental Health Commission

CHAMPIONS

- Youth Net
- Academy of Child and Adult Psychiatry
- Provincial Centre of Excellence in Child and Youth Mental Health at Children's Hospital of Eastern Ontario
- Mind your Mind
- Alberta Mental Health Board
- Children's MH Centres/Agencies
- Halifax Chair in Youth/Child Mental Health (Dalhousie)

ROLES & RESPONSIBILITIES

Full engagement of all partners throughout process

LIKELY FUNDERS

- CIHR
- Centre of Excellence in Child and Youth Mental Health at CHEO



- Canadian Youth Association Foundation
- Schizophrenia Society of Canada
- Health Canada
- Elli Lilly
- Novartis
- Public Health Agency of Canada
- Social Sciences and Humanities Research Council
- Alberta Mental Health Board
- Canadian Health Services Research Foundation
- Alberta Heritage Foundation for Medical Research
- Private Foundations

INITIAL SPECIFIC STEPS

1. Engage champions/potential partners and funders around the question
2. Information exchange/buy in.
3. Ongoing discussion of who should be involved.
4. Forum, website.
5. Scoping exercise – has relevant systematic review and environmental scan been done?
6. Refine – further develop question for systematic review of new research
7. Drafting Request For Applications
8. Scale: “typical” research grant call to establishing partner networks across country.

Cautions

- Must engage research and all partners in the initiative
- Real need for Participatory Action Research at every level
- Cultural safety, respect for cultural communities

Research Questions/Priorities #5 & 8

- **What is needed to help service providers recognize and change their own stigmatizing attitudes and behaviours?**

- **What role does the post-secondary educational system and health and professional training play in perpetuating stigma and discrimination or empowering consumers and families? What strategies might be effective in reducing stigma and discrimination with this group?**

Broad professional training focus needed:

- Health providers (practice-based training); practice and theoretical.
- Professionals around system justice/other.
- Workplace (business/other).
- Empowering practice.
- Internal champion.
- What is wrong now/what is good now/what should be doing?

LIKELY PARTNERS

- National health professional bodies that govern professionals.
- Consumers/survivors.
- Educators (training schools).
- Providers (family medicine).
- Accrediting bodies (nurses/docs/social workers/occupational therapists/psychologists/rehab).

ROLES AND RESPONSIBILITIES

- Professional organizations. to make a statement of commitment .



- Collaboration of all stakeholders – CCMHI as start place.

LIKELY FUNDERS

- Pan-Canadian Interdisciplinary Health Education I Initiative
- Provincial funding pools
- Link to quality of care in order to “sell”
- Foundations
- Corporations – Employee Assistance Programs
- CIHR

INITIAL STEPS

- Identify evidence-based practices – What is working in training?
- What is in basic curriculum?
- Information from research re: how people experience empowering practice/ stigma and discrimination practice.

CAUTIONS

- Embedded in consumer/family experiential based research
- Consistent messages across professions.
- Multiple layers re changes in practice; focus bogged down in ethics.
- Inconsistency across professional training.
- Not just theoretical – practice-based focus; culture of context.

Research Question/Priority #9

- **What are the necessary elements of effective “contact strategies” across the age span?**

LIKELY PARTNERS

- Families
- Consumer/survivors (contact people), especially those who have already made their illness public.
- Consumer-survivor organizations are the structure to connect with contact people.
- Venue partners – social services (social assistance, housing, police, etc.) (e.g. schools, workplace employers, professional associations (for MH professionals for continuing education of MH professionals), insurance companies, to influence disability policy, politicians – to influence policy and legislation.
- Media for Public Service Announcements etc. for contact through public exposure, e.g. Faces of Mental Illness.
- Professional associations to work in partnership with consumers on a contact initiative, e.g. CAMIMH.
- Universities – for researchers/investigators, e.g. PhD students would be good for this.
- National Alliance for Research on Schizophrenia and Depression (U.S.) – supports research initiatives.

ROLES AND RESPONSIBILITIES

- Families and consumers/survivors – contact people - to think of the various ways to tell their stories – to change people’s perceptions – to represent a diversity of consumer/family experiences – to present their story with peers within their workplace, for example. Those with co-morbidity could also participate in a useful strategy – e.g. someone in a diabetes support group would speak also about depression.
- Consumer-survivor organizations – the structure to connect with contact people and provide ongoing support.



- Venue partners – to provide venues – e.g. social service agencies (social assistance, housing, police, etc.) and schools, employers, professional associations (for MH professionals for continuing education of MH professionals to reduce stigma).
- Insurance companies, to influence disability policy, politicians – to influence policy and legislation.
- Media for Public Service Announcements, etc. for contact through public exposure, e.g. Faces of Mental Illness.

LIKELY FUNDERS

- Public Health Agency or Health Canada
- Mental Health Commission
- CIHR
- Workplaces (for workplace initiatives)
- Human Resources and Social Development Canada
- National voluntary organizations, e.g. CMHA, CAMIMH, MDSC.
- Pharmaceutical companies
- Health Authorities
- Provincial Health Departments
- Provincial Arms-Length Research Agencies
- Provincial voluntary organizations
- Foundations, e.g. MacArthur, Vancouver, Michael Smith Foundation.

INITIAL STEPS

1. Develop overarching principles for the research – do no harm, equitable power balance, win-win approach for consumers and those they are contacting, long-term approach, etc.
2. Find partners, bring people together to brainstorm, develop initial proposal and identify prospective funders, including alternative funders if funds

- cannot be accessed from first choice of funder, e.g. Canadian Mental Health Commission.
3. Review of research already demonstrated effective in terms of contact.
 4. Bring grassroots programs using contact strategies together for input into research proposal and possibility participate in research initiative.
 5. Identify initial strategies.
 6. Finalize proposal.

CAUTIONS

- Ensure that partners in development of proposal includes a good mix of “true believers” and sceptics, to ensure a balanced and credible perspective.
- Consider implications of disclosure – that those who disclose do not suffer negative repercussions, especially financial repercussions. Fully informed consent for consumers prior to disclosure, is critical.
- Consider effects of institutionalized stigma, e.g. insurance policies.
- Cautions re: power dynamics between consumers and others – power balance needs to be equal.
- Important to ensure research proposal includes a long-view and a variety of approaches (not just a quick and politically attractive campaign) – changing perceptions takes time and results have to be assessed over time.
- Canadian Mental Health Commission may not be established, or may be overwhelmed with research requests. If the Canadian Mental Health Commission is not established, or other major funders are not accessible for this, explore other possibilities, e.g. commitment and contributions from several NGOs, universities, in partnerships with NGOs, etc.



SUMMARY

This workshop was an exciting and pioneering activity in the area of stigma and discrimination. It was the first time that the diverse group of consumers, researchers, family caregivers, policy makers and non-government agencies came together to identify and prioritize issues for action.

The event resulted in a list of priority research questions that can serve as a starting point for more in-depth and strategic discussions about next steps in this emerging issue. A key factor that will determine how the future unfolds is whether a Canadian Mental Health Commission will be established. Delegates to the workshop are counting on the support of national leaders in this regard. However, given the commitment to action that was shown at the workshop, it is apparent that seeds have been widely sown for action in some form. The momentum established at the workshop needs to be maintained and built upon and the action plans can be used as a catalyst for next steps.

All of the groups were positive about the small group discussion for action planning. One group commented on the need to focus on the long-term, to do no harm (win/win approaches), to include sceptics on the teams and to assume there may be no Canadian Mental Health Commission. One group indicated that eliminating stigma is a long-term proposition and that educating professionals will take time – it has taken nine years to change aspects of curriculum in psychiatry.

Dr. Manon Charbonneau offered thanks to the participants on behalf of CPA for participating in the identification of important next steps in addressing stigma. She also offered thanks to Phil Upshall and Rémi Quirion for their roles in organizing the conference. As the incoming CPA president, she is looking forward to working with the participants on reducing stigma and next steps in this initiative. She indicated that she heard a clear message about the stigma that

consumers experience. Psychiatrists and consumers both bear stigma at different ends of the spectrum and are in this together. She is beginning to formulate some ideas about what she and Canadian Psychiatric Association can do to be part of the solution and she would like to hear from participants and continue to work with them on this.

Several participants noted the lack of recognition of stigma as experienced by seniors, and emphasized the need to recognize the important contribution and experiences of seniors and their role in moving forward.

Dr. Jacques Hendlisz offered to contribute \$5000 on behalf of the Douglas Hospital to help disseminate the report.

Closing remarks were made by Neasa Martin, Project Lead, thanking people for their generous contribution of time and expertise to the workshop. She pledged ongoing support of the MDSC to the issue of stigma and invited participants to look for opportunities to work together on the issue. The workshop adjourned to the Champions of Mental Health Luncheon at the Chateau Laurier Hotel.



Appendix A

Opening Panel Questions & Answers

Q. With the greater prevalence of depression in women, what are the implications of gender issues on policies and programs in Australia?

A1. Beyondblue has the largest research study and programs for post-natal depression in Australia. Other than that, we do not have any programs specific to women, although in our public awareness campaigns we do talk about the difference in prevalence rates, the reasons for it and gender differences in how people manage mental health problems. We started broad, with the initial funding. The next generation of programs will be look at gender more specifically. We also need to look at indigenous mental health issues.

A2. If we compared mental health issues in our Aboriginal communities to yours, it would be a race to the bottom. We have a lot to do there as well.

Q. The use of terminology – mental illness, for example – we do not talk about physical illness as such. We talk about heart disease, cancer, etc. Why don't we talk about brain disease? What effect does the terminology have on stigmatization?

A1. That's classic. You become the disease. What do we do about it?

A2. It's a hard issue, because naming things can help us understand them, but there is so much misunderstanding. We have to overcome that first. We need to think carefully about the language we use. What should it be?

A3. Terminology really matters.

Q. Myths feed stigma and they come from social, cultural influences. We haven't talked about this. How can you change people's attitudes? How can you teach them about the impact of language? People need to be taught how to fight stigma.

A1. That speaks to the importance of public education and awareness raising. AIDS shows us that. We, in mental health, have started to learn more about the importance of education in breaking down stigma, education about what the diseases are, individual stories, and public policy that creates a supportive environment to talk about these issues.

A2. We can achieve that in Canada. Think about how someone in a wheelchair was treated 20 years ago. Changes were achieved by law and also through campaigns to change attitudes. We need to focus on children. Discrimination is taught and learned. This is totally doable.

A3. That is the type of research we would like to support – research on what really works. With regard to terminology, we need to confront the words; we need to de-stigmatize the words, like we have done with cancer and AIDS.

Q. With regard to addictions, it is hard for people to come forward and the committee has dropped the word "addictions" from the report. Are addictions now being left in the shadows?

A. The committee did not have sufficient time or resources to address addictions, especially given the complexity of mental health issues. However, there is virtually no research going on regarding people with dual diagnoses or



integrated treatment. We have recommended more funding for this area; it is desperate for help.

Q. Something we are not talking about enough is volunteers and caregivers, who have had no training, and the impact of the mental illness of loved ones on them.

A1. The Institute of Aging is looking at the impact on carers of people with Alzheimer's disease. The issues are similar and we do need more research on this.

A2. Our research shows how difficult this is. Carers get depression themselves without some respite.

A3. It's an incredible strain on caregivers. Many of them are just lost and alone. As a mom, I also experienced a lot of stigma (being seen as a bad mom because my child has a mental illness).

Final Comment

Family members with no resources have no option except to call police – the family relationship is then damaged. I would also like to see more emphasis on groups without national provincial organizations to represent them. For example, people with borderline personality disorder or complex Post Traumatic Stress Disorder. We need to focus on and include marginalized groups in our discussions.

Report prepared by Paula Stanghetta, Workshop Facilitator

Report commissioned by: Phil Upshall, MDSC
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