

# Stigma research and anti-stigma programs: From the point of view of people who live with stigma and discrimination everyday.

What progress have we made since the Mood Disorders Society of Canada's Stigma Research Workshop in October 2006?

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#### **Table of Contents**

## Stigma research and anti-stigma programs: From the point of view of people who live with stigma and discrimination everyday.

Summary of recommendations	3
Introduction	5
Stigma and discrimination defined	5
Contributions and limits of stigma research	5
Stigma and discrimination workshop 2006 – the results	9
Steps following the October 2006 workshop	10
What else has happened since the workshop?	13
What does all this mean?	19
Conclusions and recommendations	20

**Appendix 1** Examples of research into stigmatizing attitudes among mental health professionals

**Appendix 2** Eight research priorities agreed upon at MDSC's 2006 Stigma and Discrimination Workshop

**Appendix 3** Examples of "grey literature" – reports and briefing papers Consumer blogs, writing

#### **Summary of Recommendations**

#### Anti-stigma research

- Federal and provincial governments must model leadership in opposing stigma and discrimination towards those living with a mental illness. They must increase funding for mental health research, in general, and anti-stigma research (leading to action) in particular. They must also strengthen anti-discrimination laws and enforcement.
- Anti-stigma research must be tied to action. New methods (or under-utilized methods such as qualitative and participatory action research) must be embraced and funded.
- Consumers and families must be an integral part of anti-stigma research, especially at the outset when questions are being formulated.
- Research findings must be disseminated in non-traditional ways so that
  consumers, families, and community agencies can make use of them.
  Researchers must stop talking only to themselves and engage with the people
  who are the subjects of their research and those who are supposed to be
  utilizing its findings.
- The Institute of Neurosciences, Mental Health and Addictions needs to move its anti-stigma research agenda forward, as a priority.

#### Health and mental health professionals

- Health and mental professions must confront the fact that stigma and discrimination towards people with mental illness is expressed, and expressed often, within their own ranks. Some professionals have taken leadership roles in this acknowledgement. Others have not yet done so. Acknowledgement is only a first step. Professional under- and post-graduation curricula must change, as must the commonplace tolerance of workplace expressions of stigma.
- Those involved in the provision of emergency department services must revise the Canadian Triage and Acuity Scale (CTAS) so that it is more effective in assessing psychiatric emergencies. These changes would go a long way in reducing wait times for those presenting with psychiatric difficulties in emergency rooms across the country.

#### Anti-stigma campaigns

- There is a need to conduct a Canadian environmental scan that documents all anti-stigma campaigns across the nation. These local activities will serve as a roadmap of innovation and best practice for others wanting to develop their own campaigns and, particularly, for the Mental Health Commission as it launches its own.
- The Mental Health Commission of Canada must continue to move quickly from planning to action, implementing its anti-stigma campaigns (based on best

practices and including evaluation components) as soon as possible. It must reaffirm its commitment to involving consumers and family members in all aspects of these campaigns. Involvement does *not* mean simply presenting finalized plans or asking for approval of already-developed messages. It means that consumers and families lead MHCC campaigns and are part of all decision-making and implementation activities.

#### Recovery

- Recovery philosophy is widely embraced but not widely practiced. Hope can be a scarce commodity for those who work on the front lines and see exactly how difficult life can be for people with mental illness, complicated by poverty, violence, and ghettoized living conditions to name only a few of the indignities suffered. But the human spirit is courageous. This is well known by those of us who have recovered. We were there once, more down and out than can be imagined. But we made it and we have an obligation to help those who are still struggling. Recovery is not just a theoretical concept. Nor is it only to guide clinical work and medical intervention. It must also be the ever-present message when peer meets peer.
- In order to facilitate the recovery model, the medical system must become truly patient centred. To do this, it must recognize that psychosocial treatments are part of the continuum of care and become more collaborative in the provision of primary care by including the greater engagement of mental health professionals, peer support and self help. Medicine, psychiatry and all mental health professionals must more consistently include consumers - and their families (where appropriate) - in treatment decisions.

#### Introduction

In October, 2006, the Mood Disorders Society of Canada (MDSC) held a workshop in Ottawa on the issues of stigma and discrimination. This event was the first research workshop to be inclusive of all mental health professionals, service providers, researchers, consumers and families, and others with an interest in stigma and mental health issues.<sup>1</sup>

Today, as then, stigma and discrimination remain the number one concern for consumers and families because they live with its effects everyday. Since 2006, there have been numerous forums and stigma has gained some attention from those who fund research. The reality remains that changing attitudes and beliefs – let alone behaviours – remains a slow process.

This paper examines the contributions and limits of stigma research - the original impetus for the workshop. It reviews and comments on the findings from the workshop and presents further MDSC thoughts and activities. It then documents national and international anti-stigma activities since that time and offers a series of recommendations for forward movement. It asks the question: What progress have we made?

#### Stigma and discrimination defined

As a brief review of what, specifically, we're talking about...

**Stigma** is defined as negative, disrespectful and untrue judgments about you based on what people think they know about you – and your situation.

In contrast, *discrimination* involves negative and disrespectful actions against you.

**Self-stigma** occurs when you begin to believe the negative opinions about you and start to think that you deserve to be called names and denied opportunities.

**Stigma and discrimination by association** involves negative judgments about - and disrespectful actions against - family members, caregivers and mental health professionals.

#### Contributions and limits of stigma research

The basis for the Stigma and Discrimination Workshop (2006) was to advise researchers on questions that are of interest to consumers and families. Recent trends in research, supported by the Canadian Institutes of Health Research (CIHR) and, in particular, the Institute of Neurosciences, Mental Health and Addiction (INMHA), have sought to involve subjects (in this case, consumers and families) in research – from formulating questions, to gathering, analyzing and interpreting data, and in disseminating findings.

<sup>&</sup>lt;sup>1</sup> The workshop was principally funded by Health Canada and the Institute of Neurosciences, Mental Health and Addiction (INMHA), one of the divisions of the Canadian Institutes of Health Research (CIHR).

<sup>&</sup>lt;sup>2</sup> The background paper and proceedings report are available at <a href="www.mooddisorderscanada.ca">www.mooddisorderscanada.ca</a> Mood Disorders Society of Canada (March 2009): Stigma research and anti-stigma programs: From the point of view of people who live with stigma and discrimination everyday.

Slowly, and it must be emphasized that it is very slow, the traditional definition of "expert" is expanding to acknowledge that first hand experience (experiential expertise) has a role to play in research, as well as policy making, program planning and service delivery.

While academia is a prime source of scientific discovery, it is also an institution built on rigid tradition, slow to change and suspicious of new methodologies and new voices. Nonetheless, the Mood Disorders Society of Canada has witnessed the desire to change and has been pleased to have been a partner in numerous research projects whose goals were and are to change the lives of those affected by mental illness and their families.

#### a) Contributions

## Confirmation regarding how very hard it is to change attitudes and behaviors

While change may not be at the pace we'd like, it is clear that stigma research has made contributions that are valued. For example, consumers and families despair at the entrenched nature of negative beliefs and attitudes towards mental illness in their communities and among their friends. Research has confirmed their experience. It is extremely hard to shift beliefs and ever harder to change behaviour. While this is not good news, it is at least a shared acknowledgement of reality.

#### Just educating people doesn't work

Consumers and families have long held the belief that educating the public about mental illness is the path to change – 'if they just knew the facts, they'd behave better.' Research has shown that this common sense approach does not work. In fact, some research goes even further by exposing the paradox that those who are the most educated about mental illness, mental health professionals, can hold the same or even more stigmatizing beliefs than the general public.<sup>3</sup> On this last point, studies that examine stigma and discrimination among professionals are rare and acknowledged by MDSC as courageous. See Appendix 1 for a review of some of these papers.

#### Identifying what does work

Research has documented which sorts of anti-stigma campaigns actually work.<sup>4</sup> For example, consumers and families must be engaged in all aspects of the campaign and programs must be customized to local circumstances. Broad national campaigns cost a lot of money and have little effect. Repeated, positive, direct contact with

<sup>&</sup>lt;sup>3</sup> Mistik, S, Turan, T. (2005). Changes in medical students' opinions and attitudes towards mental illness. <u>Middle East Journal of Family Medicine</u>, vol 3 (4). Available at: http://www.mejfm.com/journal/Sep05/Change in Medical Students.htm

This study finds that medical students' negative attitudes towards those with psychiatric illness actually increase over their training period.

<sup>&</sup>lt;sup>4</sup> For a full discussion, see: Martin. N. & Johnston, V. (2007). A time for action: Tackling stigma and discrimination. Available at:

http://www.mentalhealthcommission.ca/English/Pages/AntiStigmaCampaign.aspx This paper offers a discussion on what works.

people who have mental illness works, as does targeting certain influential groups such as decision-makers, health and mental health professionals and the media.

#### b) Limitations

#### Research for the sake of research

The traditions of academic enquiry can be uncritical of researchers asking questions and conducting studies valued exclusively by themselves (curiosity-driven research), by funders or by those that decide tenure - but which are irrelevant to consumer and family needs. Here, the consumer voice is either not sought or ignored if raised. The results produced, in the view of MDSC, are of questionable value, have little or no impact on consumer and family lives and represent a less than optimum use of public funds. Examples of such research are studies that, yet again, document the extent of stigma (we know it is wide-reaching), parse it into a taxonomy of types (stigma is stigma no matter what you call it), and those that expand theoretical notions on why stigma exists (its origins in human behaviour doesn't much matter to those who deal with it daily).<sup>5</sup>

## It is difficult to reduce complex, multi-faceted subjects to narrowly focused research questions

The scientific tradition requires researchers to ask questions in particular ways and to conduct enquiry with approved methodologies. If they do not adhere to time-honoured approaches, their findings are criticized as invalid and their work judged to be un-publishable. However, the existence of stigma – and the experience of stigma and discrimination – are subject to complex human and social forces that don't reduce well to the focused activities of research. While bits and pieces of the experiences of stigma and discrimination can be subjected to traditional scientific investigation, the whole appears irreducible.

Consumers and families, like many diverse groups (immigrants, ethno-racial peoples, First Nations, Inuit and Métis – as only a few examples), have had experiences of willingly participating in mainstream research but without any access to results - a failure of the knowledge translation process. More disheartening, research "facts and figures" have been presented in ways that show that researchers have completely misunderstood the subjects' reality and, in cases that are all too common, results are used to preserve stereotyping, stigma and discrimination. To guard against such misappropriation, these groups now insist that they be involved in all aspects of research that concerns them, from the development of questions, to the choice of methods to the analysis of results and dissemination of findings. Their preferred methods are qualitative and participatory action research (PAR). Qualitative methods are gaining validity and are aimed particularly at the complexity of human experience. However, these and other consumer and family preferred methodologies, such as participatory action research, do not attract the attention of funders easily and remain on the fringes of scientific activity - to the point that many peer reviewers do not consider them scientific at all.

<sup>&</sup>lt;sup>5</sup> For a fuller discussion on stigma research, see: Everett, B. (2006). Stigma: The hidden killer. Available at: <a href="http://www.mooddisorderscanada.ca/paqe/research-papers-reports">http://www.mooddisorderscanada.ca/paqe/research-papers-reports</a>
Mood Disorders Society of Canada (March 2009): Stigma research and anti-stigma programs: From the point of view of people who live with stigma and discrimination everyday.

#### The disconnect between research and action

There is a mismatch of urgencies between researchers (funders and academic journals) and consumers and families. Consumers want action on stigma and discrimination immediately, not after years of study and reflection seeking just the right approach, the right plan and the right implementation strategy.

In addition, the publication of research findings, most frequently in small circulation learned journals, is all too often the end point of the exercise. This leaves non-governmental organizations and others alone in advocating for change and government funders to act – or not to act – as the spirit moves them. Effective knowledge translation would mean that those who need to know or who are entitled to know are the recipients of new knowledge. Without concerted advocacy by all, *not* acting is by far the easiest route for governments to take.

The above critique may be somewhat more plain-spoken than policies that emanate from the Canadian Institutes of Health Research, but, at bottom, the sentiment is the same. CIHR's knowledge transfer mandate states:

" .... the creation of new knowledge often does not on its own lead to widespread implementation or impacts on health. Secondly, with the increased focus on research governance and accountability from the federal and provincial governments, as well as from the public, these parties would like to see the benefits of taxpayer dollars that are invested in health research by moving research into policy, programs and practice."

#### Slow dissemination of important findings

What limited evaluation research that exists - and the even smaller pool that shows positive outcomes for anti-stigma programs - can easily be ignored when program extensions are sought from funders. The slow dissemination of research and its propagation in obscure or exclusive domains means that replication of good ideas is glacial. Further, there is no broad-based imperative to base anti-stigma initiatives on tried and true ideas – leaving governments and other granting bodies far too often funding proposals that are long on enthusiasm but short on proven results.

#### Hard to ask hard questions

As is so often the case in areas of our society where tradition is deep, researchers can shy away from asking the really hard questions. Their fears are based on reality. Despite protestations of freedom of enquiry and voice, controversy is not welcome in academia and funding bodies too often want to build on previous work rather than take a risk on charting new, especially non-mainstream waters.

#### Only certain researchers can compete successfully for grants

While it is not generally known, research granting bodies that issue requests for proposals for stigma research (and other topics) are inaccessible to non-governmental organizations who would like to participate. One major issue is that funders assume the principle investigator's salary is paid through his or her employer

<sup>&</sup>lt;sup>6</sup> See: <a href="http://www.cihr-irsc.gc.ca/e/29418.html">http://www.cihr-irsc.gc.ca/e/29418.html</a>
Mood Disorders Society of Canada (March 2009): Stigma research and anti-stigma programs: From the point of view of people who live with stigma and discrimination everyday.

- typically a hospital or a university. Some of the very largest granting bodies in Canada (such as the Canadian Institutes of Health Research - CIHR) restrict participation to university associated researchers – shutting out non-profit organizations and consumer and family groups completely.

In addition, it is a right of passage for developing researchers to apply for grants, fail and apply again and again, until they are finally able to convince peer reviewers that their questions and methods are worthy of funding. During this process, they are fully employed and supported in their development by numerous colleagues and peers within their institution. As they develop a track record of successful grantsmanship (peer reviewers have come to know and trust their work), they become ever more competitive in the crowded applications process. While timehonoured and not without validity, this tradition serves to advantage professional researchers from large institutions, meaning that perfectly well-qualified researchers working with non-traditional groups - such as community agencies or consumer and family groups (for example the Schizophrenia Society) are uncompetitive for at least three reasons. Smaller organizations can't afford to pay researchers themselves so they are automatically ineligible because they ask that the grant cover the salary of the principle investigator They are also likely to be advancing questions (and methods) that may be viewed as outside the research tradition. Third, the smaller organizations do not have the funds to devote solely to the try- and try again peer review process that is the preferred way of doing things in academia.

It is MDSC's position that anti-stigma research for the sake of anti-stigma research is no longer acceptable. Research must result in the creation of new and practical knowledge which, through required and effective knowledge translation mechanisms, can lead to action.

#### Stigma and Discrimination Workshop (2006) – the results

The purpose of the workshop was to develop a broad-based consensus on recommended research questions focused on stigma and discrimination for use by INMHA as well as by the (then) planned Mental Health Commission of Canada. Specifically, the recommendations were to proceed from a consumer and family lens – albeit with many other stakeholders in attendance.

To that end, the workshop delegates (90 in number) included representatives from the research community in general, CIHR and INMHA in particular, law and justice, government policy makers, youth, seniors, international leaders in the subject matter, politicians and of course, consumers and families.

A day of spirited dialogue produced a consensus on eight priorities – each of which was to be guided by the principles of recovery<sup>7</sup> and consumer and family inclusion. See Appendix 2 for a review of the priorities along with brief commentary.

The eight recommendations illustrated how absolutely crucial it is to involve consumers and families in formulating research questions – about all sorts of things, not just stigma and discrimination.

Recovery is defined as a cure. It is living well and fully – despite life's challenges. Mood Disorders Society of Canada (March 2009): Stigma research and anti-stigma programs: From the point of view of people who live with stigma and discrimination everyday.

Four out of the eight recommendations concerned stigma and discrimination among the health and social service professions, including the mental health professions. In literature, stigma and discrimination towards psychiatric clients among professionals is an extremely rare topic. Among consumers and families it is THE topic.

Having been the target of hurtful judgments and harsh criticisms in our lives, we at MDSC are mindful that these workshop findings are hard for professionals to hear – let alone act upon.

#### Steps following the October 2006 workshop

While it was not the mandate of the workshop to develop a more nuanced discussion of stigma and discrimination, subsequent work at MDSC (and in other venues) went on to do so.<sup>8</sup>

- **a) Stigma and discrimination among professionals** a MDSC paper available at: <a href="http://www.mooddisorderscanada.ca/page/research-papers-reports">http://www.mooddisorderscanada.ca/page/research-papers-reports</a> . This paper argues the following:
  - 1. Professionals, in particular mental health professionals, have been strong advocates for reducing stigma and discrimination. For example, the Canadian Collaborative Mental Health Initiative produced a Charter where 12 groups, many of which were national professional associations and, of these, the mental health professions were well represented, signed a commitment for their organizations to "develop and implement strategies for reducing stigma and discrimination associated with mental illness that can be applied across various settings (e.g., health, community, workplace, school).<sup>9</sup>
  - 2. Mental health professionals are themselves, targets of stigma and discrimination.

"Psychiatrists are not "real" doctors."10

"People feel like they are giving up "real" medicine to do psychiatry."11

"Some doctors are still prejudiced against patients with mental illness and I have been told, 'you work with loonies.' If one doctor can say this to another, what hope can we hold out for the rest of society?"  $^{12}$ 

Film characterizations of psychiatrists and therapists portray them as either evil or bumbling.<sup>13</sup>

<sup>&</sup>lt;sup>8</sup> MDSC (2007). Stigma and discrimination as expressed by mental health professionals. Available at: http://www.mooddisorderscanada.ca/page/research-papers-reports

<sup>&</sup>lt;sup>9</sup> The full text of the Canadian Collaborative Mental Health Initiative Charter (March 2006) is available at: http://www.ccmhi.ca/en/products/charter.html

<sup>&</sup>lt;sup>10</sup> Persaud, R. (2007). Medicine's unsung heroes: why does psychiatry have such an image problem? <u>Canadian Psychiatry Aujourd'hui</u>. 3(6). See: <a href="http://publications.cpa-apc.org/browse/documents/262">http://publications.cpa-apc.org/browse/documents/262</a> <sup>11</sup> Collinson. K. Specialty questions: Psychiatry. University of Alberta.

Priory Group, Roehampton Health Care, (South London) UK (August 2007). *Crying shame.* Dr. Natasha Bijilani, Consulting Psychiatrist, as quoted on pg. 12. See: <a href="http://www.prioryhealthcare.co.uk/webfiles/news/crying%20shame.pdf">http://www.prioryhealthcare.co.uk/webfiles/news/crying%20shame.pdf</a>

Psychiatrists are regular targets of the most scathing attacks not typically aimed at other medical specialties.<sup>14</sup>

Stigma against mental health professionals (of all types) and mental health researchers has also been identified as a barrier to the free flow of scientific knowledge that could lead to better treatment, improved policies and greater investment in the Canadian mental health system. This stigma is seen as endemic in the scientific, political and medical communities.<sup>15</sup>

3. Leaders in high profile mental health professions, for example, the Canadian Psychiatric Association, have spoken publicly.

Dr. Manon Charbonneau, past president of the Canadian Psychiatric Association says: "But stigma is not solely the domain of others. As professionals we need to be conscious of our own stigma-prone behaviours or the internalized stigma we may perpetuate." <sup>16</sup>

While acknowledging these realities, it nonetheless cannot be denied that health professionals, including mental health professionals, hold negative beliefs about people with mental illness and act in discriminatory ways – as Dr. Charbonneau courageously acknowledged.

4. Mental health professionals as consumers

This fact has been further confirmed by a newer set of voices; people who have experienced mental illness or addiction and have gone on to become, themselves, mental health professionals.

Cheryl Peever, manager and social worker at the Centre for Addiction and Mental Health (CAMH) and one of the 2006 recipients of CAMH's Courage to Come Back awards reported what can happen when a mental health professional reveals her experiences with mental illness and addiction – in a workplace dedicated to helping people with exactly these problems.

"The truth came out awkwardly. An announcement was posted on the staff bulletin board... The dominant (reaction) was silence. People didn't know what to say so they didn't say anything. As she expected, there were a few hurtful comments. What surprised her were the furtive congratulations. 'I really respect you, but I didn't want anyone to see me talking to you,' one colleague

<sup>&</sup>lt;sup>13</sup> Byrne, P. (2003). Psychiatry and the media. <u>Advances in Psychiatric Treatment</u> Vol 9 p. 135 – 143. Available at: <a href="http://apt.rcpsych.org/cgi/content/full/9/2/135">http://apt.rcpsych.org/cgi/content/full/9/2/135</a>

<sup>&</sup>lt;sup>14</sup> As only one example, see the Coalition against Psychiatric Assault at:

http://capa.oise.utoronto.ca/links.html

15 Strategic Initiative – Meeting the national challenge: Putting mental health and addiction knowledge into practice (2006). A report produced by the Institute of Neurosciences, Mental Health and Addictions in collaboration with the National Collaborating Centre for Aboriginal Health. See: <a href="http://www.cihr-irsc.qc.ca/e/31322.html">http://www.cihr-irsc.qc.ca/e/31322.html</a>

<sup>&</sup>lt;sup>16</sup> Charbonneau, M. (2007). Identity, humanity, generativity.. A year in review. <u>Canadian Psychiatry Aujourd'hui</u>. 3(5). See: <a href="http://publications.cpa-apc.org/browse/documents/262">http://publications.cpa-apc.org/browse/documents/262</a>

told her. 'I'm proud of you' said another making sure no one was in earshot."  $^{17}$ 

In a second example,<sup>18</sup>

"When Nigel Bart decided that his experience reining in his demons made him ideally suited to fill a counsellor opening at a Winnipeg public mental health agency, it had been seven years since he had been tormented by the voices in his head. That he was a local man with a university degree and a passion for mental health issues had him sailing through the interview, he recalled – until he mentioned his schizophrenia. 'I could see them just brace themselves a little bit,' said Mr. Bart, 32, an artist who now runs a studio to benefit mentally ill artists. 'They called me later to tell me that I didn't get the job and when I asked them why, they said it was because I made an unhealthy disclosure. That's what they called it.'"

## b) Emergency room physicians and psychiatrists meet to discuss wait times in the ER

In January 2008, MDSC hosted an invitational roundtable on psychiatric patient waits in Canada's emergency departments. Attendees included emergency physicians and psychiatrists and representatives from their respective associations (for example, the Canadian Association of Emergency Physicians - CAEP). Delegates acknowledged that it was the first time a national panel of experts had gathered together to address this important issue. Stigma and discrimination against people with mental illness in Canada's emergency departments (EDs) was an extremely sensitive topic for delegates who confined their recommendations to procedural and system short-comings. Nonetheless, they acknowledged that there are real problems in EDs and that patients with psychiatric problems are not being served well. To that end, delegates offered a recommendation that asked for a review of the Canadian Triage and Acuity Scale (CTAS) which is the method by which emergency room personnel assign priority to patients' problems (who is seen first and who gets to wait).<sup>19</sup>

#### c) Consumers and families add to the literature

Consumer and families, themselves, are adding to the literature on stigma with their own blogs, first person accounts, books and plays. This voice is not traditionally recognized or referenced in academic circles because it is not part of scientific enquiry. The more formal of these works (reports or workshop findings as only two examples) are called "grey literature," meaning not as reliable or as important as studies produced by researchers, noting that blogs (understandably) don't meet the test of the grey literature categorization. MDSC considers all forms of these creative works, experiential accounts and analyses to be of immense value. See Appendix 3 for a bibliography of consumer and family (and others) writings on stigma and discrimination.

<sup>&</sup>lt;sup>17</sup> Goar, C. (Monday, Oct 15, 2007). Mental illness in the workplace. The Toronto Star.

<sup>&</sup>lt;sup>18</sup> Andreatta, D. (Tuesday, November, 2007). Struggling against stigma. The Globe and Mail.

<sup>&</sup>lt;sup>19</sup> A proceedings report is available at: <a href="http://www.mooddisorderscanada.ca/page/research-papers-reports">http://www.mooddisorderscanada.ca/page/research-papers-reports</a>

## d) Other groups raise the issue of degrees of stigma, multiple stigmas and health inequity

While there appears to have been some improvement in the general public's understanding of mental illnesses such as depression, 20 "real" mental illness defined as schizophrenia is still viewed as hopeless - and sufferers as dangerous. While experiences of stigma and discrimination are painful in all their forms, there are certain categories to which people are assigned that are so negative that their whole identities are overwhelmed. These "spoiled identities" were first written about by Erving Goffman in the 1950s and although treatments have progressed and the world has become somewhat more understanding, there are still psychiatric diagnoses that produce such deep wounds to the perception of self that people must not only recover from the illness, they must recover from the label.

People with concurrent disorders (mental illness combined with substance abuse)<sup>21</sup> and people with dual diagnosis (developmental disabilities and mental illness)<sup>22</sup> are adding to the dialogue by pointing out that many are subjected to multiple stigmas that relate to their health or disability status, but are also based on ethnicity, race, sexual orientation or any number of "differences." While the stigma attached to mental illness is acknowledged to interfere with recovery, experiences of multiple stigmas are associated with social inequality and disadvantage, leading to poor treatment in the health system that is avoidable and unfair, resulting in even lower health and social status. Thus, health inequity<sup>23</sup> is an additional consequence of multiple stigma and discrimination that must be acknowledged in discussion.

#### What else has happened since the workshop?

All over Canada, for many decades, there have been countless local anti-stigma campaigns, mostly volunteer led, small and with minimal budgets. For example, there were 86 known local campaigns associated with Mental Illness Awareness Week in 2008.

As a further example, in the wake of the workshop, MDSC mounted its own antistigma campaign that involves a small blue elephant (called the Elephant in the Room). Recipients display the elephant in their workplace or home and use it as a prop to start conversations about mental illness or, in a more passive way, as a signal that they are open to discussing mental illness in a non-discriminatory manner – if workers or visitors want to. The elephant is accompanied by an anti-stigma pamphlet.<sup>24</sup> The elephant has been particularly welcomed by human resources

<sup>&</sup>lt;sup>20</sup> A report from the Canadian Alliance for Mental Health and Mental Illness (CAMHMI). Available at: <a href="http://www.camimh.ca/mental health literacy.html">http://www.camimh.ca/mental health literacy.html</a>

For a discussion of stigma related to concurrent disorders, see the Centre for Addiction and Mental Health's pamphlet at:

http://www.camh.net/Care Treatment/Resources clients families friends/stigma brochure.html

<sup>&</sup>lt;sup>22</sup> For the National Coalition on Dual Diagnosis's position statement, including remarks on multiple stigmas, see: <a href="http://care-">http://care-</a>

id.com/index.php/publisher/articleview/?PHXSESSID=cdfcbc772207eff186d3bf1de54f97a2&/1/frmArticleID/22/staticId/37/

Gardner, B. (2008). Health equity discussion paper – Executive Summary. Published by the Toronto Central Local Health Integration Network. Available at: <a href="http://www.torontocentrallhin.on.ca/publicationandreports.aspx?ekmensel=e2f22c9a">http://www.torontocentrallhin.on.ca/publicationandreports.aspx?ekmensel=e2f22c9a</a> 72 206 btnlink

Available in hard copy or online at: http://www.mooddisorderscanada.ca/

specialists and teachers who use it to provide permission to employees/students to talk about a subject that they might otherwise keep secret. Having it in plain view on desks announces a stigma free environment.

There is no national directory that records all this activity and very little evaluative research that measures its effect. Nonetheless, these campaigns matter to those who mount them and to the communities that receive them. The activities profiled below are neither more nor less that these local activities. They have been selected because of their national and/or international reach – or because they represent new ways or new angles of approaching stigma and discrimination.

#### **INMHA**

The findings of the workshop have been utilized to craft Request for Proposals that, presently, are awaiting funds so that announcements can be made.

#### Wide dissemination of the MDSC stigma workshop recommendations

The workshop was unique because of the breadth of diversity among delegates and the level of consensus on findings. Its reports have been disseminated widely in Canada, but also the United Kingdom, Europe and Australia. Health Canada and the federal Minister of Health have both accepted the findings.

#### **Activity among the professions**

Some professional groups have (gingerly) begun to examine the possibility that stigma and discrimination towards people with mental illness exist within their own ranks.

**The Association of Faculties of Medicine of Canada:** The Association has received the report and acknowledged at senior levels the potential for undergraduate and graduate education in mitigating the expression of stigma and discrimination toward people with mental illness in the medical professions.

Canadian Psychiatric Association: With the leadership of Manon Charbonneau, the Canadian Psychiatric Association created a stigma working group and recruited Dr. Heather Stewart (who is the Mental Health Commission's Senior Consultant for its Anti-stigma and Anti-discrimination Campaign as mentioned below) to design a survey of the membership. The survey was conducted at the CPA conference in September 2008. The survey asked for comments on stigma as expressed in targeted areas such as the emergency room, through insurance companies and with general practitioners. Further, it asked for psychiatrists' personal stories of stigma and discrimination directed toward their profession. The results yielded almost 400 stories. The survey also identified stigma towards people with mental illness in emergency rooms as the number one priority for respondents. The results of the survey have not yet been published.<sup>25</sup>

<sup>&</sup>lt;sup>25</sup> This information come courtesy of Francine Knoops, CPA, February 19<sup>th</sup>, 2009. Mood Disorders Society of Canada (March 2009): Stigma research and anti-stigma programs: From the point of view of people who live with stigma and discrimination everyday.

An important learning from the CPA approach was that a non-accusatory tone intended to start a dialogue is the most effective way to access the subject of stigma and discrimination - among professionals - and towards mental health professionals.

Since that time, two national working groups have convened to further examine stigma and discrimination towards people with mental illness among the helping professions. The first group involves family physicians, pediatricians, emergency room physicians, addictions specialists and other physicians – working with the Canadian Medical Association. The second is a Mental Health Table of the Regulated Health Professions which includes physicians and psychiatrists - but also many other professional groups.

**Canadian Medical Association:** In 2008, the Canadian Medical Association passed a number of motions aimed at ending discrimination in the health sector towards people with mental illness. Specifically, these motions called for collaborative action between physicians and psychiatrists to ensure better access to mental health care and for improved funding for mental health services which lags so far behind other areas of health care.<sup>26</sup>

**Canadian Association of Occupational Therapists:** In a Calgary meeting in June 2008, Professor Terry Krupa accepted the Muriel Driver Award from the Canadian Association of Occupational Therapists. Her address to the audience addressed stigma towards the mentally ill among occupational therapists.<sup>27</sup>

**Canadian Psychological Association:** The 2009 winter edition of *Psynopsis,* Canada's psychology newspaper published by the Canadian Psychological Association, calls on psychologists to confront stigma where and when they encounter it - but to begin by first acknowledging the existence of stigma and discrimination toward people with mental illness within their own membership.<sup>28</sup>

#### The Mental Health Commission of Canada

Subsequent to the 2006 MDSC workshop, the Mental Health Commission of Canada (MHCC) was established. True to its promise, the Commission has been planning a series of anti-stigma campaigns. To that end, it commissioned a background paper on stigma and discrimination,<sup>29</sup> published an operational plan (September, 2008) and held a planning session in December, 2008.<sup>30</sup> MHCC has also appointed Professor Heather Stewart as

<sup>&</sup>lt;sup>26</sup> Canadian Health Reference Guide, January 20, 2009. Canadian psychiatrists press for equal treatment of mental illness and petition fellow physicians to fight discrimination towards mentally ill persons.
<sup>27</sup> The address was especially emotional in light of the very recent and shocking murder/suicide in Calgary. Joshua Lall, allegedly in the grip of a psychotic episode, murdered his tenant, his wife and their two children. Both Lalls were occupational therapists. Personal communication: Professor Krupa.
Psynopsis is available at: <a href="http://www.cpa.ca/home/">http://www.cpa.ca/home/</a>

<sup>&</sup>lt;sup>29</sup> Martin. N. & Johnston, V. (2007). A time for action: Tackling stigma and discrimination. Available at: http://www.mentalhealthcommission.ca/English/Pages/AntiStigmaCampaign.aspx

<sup>&</sup>lt;sup>30</sup> See: <a href="http://www.mentalhealthcommission.ca/English/Pages/AntiStigmaCampaign.aspx">http://www.mentalhealthcommission.ca/English/Pages/AntiStigmaCampaign.aspx</a> Mood Disorders Society of Canada (March 2009): Stigma research and anti-stigma programs: From the point of view of people who live with stigma and discrimination everyday.

Senior Consultant for its Anti-stigma and Anti-discrimination Campaign. The focus for the MHCC's campaign is on:

- Youth especially local projects that engage youth speaking to youth
- The expressions of stigma and discrimination among health and mental health care providers.

Given the findings of the MDSC workshop, this double-pronged focus is particularly welcome.

The Commission has adopted a social marketing approach to its campaigns and is moving forward aggressively.<sup>31</sup>

#### The 2008 Globe and Mail series

Entitled Breakdown - mental health crisis: Into sight, into mind, the series was an historical first for a number of reasons: its thoroughness, its use of web technology to encourage interactiveness, its solicitation of readers' stories (called "speak your mind"), the space and the length of time devoted to the subject (articles ran from June until November 2008), and for its use of the vernacular rather than mimicking stilted clinical language ("look good but feel like crap"). The series also struck a balance between facts and figures, personal stories, an exploration of stigma, 32 a prescription for change ("face it, fund it, fix it -12 steps")<sup>33</sup> and a call to action from the editor addressed to Canadian legislators.<sup>34</sup> It concluded many months later with a poignant essay from Lucy Maude Montgomery's granddaughter (directly attributable to the impact of the series) entitled, The heartbreaking truth about Anne's creator: Kate Macdonald reveals a long-held secret about her grandmother, one of Canada's most beloved authors. 35 The article revealed that both Lucy Maude and her husband had suffered from depression and that Lucy Maude had committed suicide.

#### The mental health literacy project

This project produced a *National integrated framework for enhancing mental* health literacy in Canada (2008).<sup>36</sup> Lack of mental health literacy results in an inability to recognize mental illness in one's self or others, a resistance to

anti-stigma programs: From the point of view of people who live

with stigma and discrimination everyday.

 $<sup>^{31}</sup>$  More information can be found at the Commission's website  $\underline{\text{www.mentalhealthcommission.ca}}$ 

 $<sup>^{32}</sup>$  Kirby, M. (June 27, 2008). Stigma against the mentally ill is getting worse and better, as attitudes polarize. The Globe and Mail. Available at:

http://www.theglobeandmail.com/servlet/story/RTGAM.20080626.wmhessay0628/BNStory/mentalhealth/
<sup>33</sup> Picard, A. (June 27, 2008) A 12 step program for Canada: Setting priorities and solutions to address the mental health crisis. The Globe and Mail. Available at: http://www.theglobeandmail.com/servlet/story/RTGAM.20080627.wmhsolutions28/BNStory/mentalhealth

Greenspon, E. (June, 2008). A call to action: A letter to legislators for the Globe and Mail editor-inchief. Available at: <a href="http://www.theqlobeandmail.com/breakdown/action">http://www.theqlobeandmail.com/breakdown/action</a>
Available at:

 $<sup>\</sup>frac{\text{http://www.theglobeandmail.com/servlet/story/RTGAM.20080919.wmhmontgomery0920/BNStory/mental health}{\text{health}}$ 

A report from the Canadian Alliance for Mental Health and Mental Illness (CAMHMI). Available at: <a href="http://www.camimh.ca/mental health literacy.html">http://www.camimh.ca/mental health literacy.html</a>
Mood Disorders Society of Canada (March 2009): Stigma research and

seeking help even when you know something is wrong, and use of damaging remedies or engaging in dangerous behaviors as a way of managing symptoms. It is also a block to self-efficacy and self-management. Mental health literacy is a concept that tackles stigma and discrimination from a new direction, that of individual (and family) knowledge, skill, and self-empowerment. Mental health literacy could prove to be a new and useful tool in anti-stigma work.

#### **Statistics Canada**

The Canadian Community Health Survey has developed a mental health stigma and discrimination test questionnaire for inclusion in its next survey. It was tested between May and June 2008 to ensure it will provide quality data.<sup>37</sup>

#### **Mental Illness Awareness Week**

Held every year in October, the Mental Illness Awareness Week (MIAW) campaign has grown exponentially in the attention it receives and the reach that it has achieved. This past year, 24 organizations sponsored the luncheon in Ottawa. There were 27 nominees for the *Face of Mental Illness* award and five winners. Requests for the MIAW brochure (in English and French) exceeded all expectations with 88,725 copies distributed. There was excellent coverage in the broadcast and print media, reaching 20 millions Canadians. The central MIAW campaign provides kits and materials to over 5,000 local groups including non-profit organizations, businesses and government offices for local events. Eighty-six groups posted their activities on the MIAW website (<a href="https://www.miaw.ca">www.miaw.ca</a>). This years' Champions of Mental Health Awards went to:

- Public sector award: the Right Honourable Steven Harper, Prime Minister
- First Nations, Inuit and Métis award: Mary Simons, President of Inuit Tapiriit Kanatami
- Research award: Dr. Alain Lesage, Centre de recherché Fernand Séguin
- Business award: Lloyd Craig, CEO, Coast Capital Savings
- Media award: Shelagh Rogers, CBC Host

#### More personal testimonials from public figures

Incidence rates for mental illness are clear. One in five Canadians will experience a mental illness in their life time. The rest will support a loved one through the experience. Mental illness touches most lives and people are beginning to speak out publicly about their own or a loved one's experience.

In August 2008, the parliamentary assistant to the Alberta Minister of Health, Raj Sherman, recounted his own brush with suicide where, as a distraught sixteen year-old, he stood in front of an oncoming car on a darkened road. The driver swerved at the last minute and only grazed him. He didn't tell

<sup>&</sup>lt;sup>37</sup> Further information and the test survey is available at: <a href="http://www.statcan.gc.ca/cgi-bin/imdb/p2SV.pl?Function=getSurvey&SDDS=5152&lang=en&db=imdb&adm=8&dis=2">http://www.statcan.gc.ca/cgi-bin/imdb/p2SV.pl?Function=getSurvey&SDDS=5152&lang=en&db=imdb&adm=8&dis=2</a> Mood Disorders Society of Canada (March 2009): Stigma research and anti-stigma programs: From the point of view of people who live with stigma and discrimination everyday.

anyone what he had done – but used his own story to announce his government's investment in children's mental health.<sup>38</sup>

Kate Heartfield, a journalist and member of the Ottawa Citizen's editorial board began her February 2009 story on anxiety, depression and obsessive compulsive disorder (OCD) with her own partner's struggle – and her efforts to cope and help through the recovery.<sup>39</sup>

The Centre for Addiction and Mental Health's campaign, Transforming Lives<sup>40</sup> has seen a number of prominent Canadians step forward with their own family stories.

- Harry Rosen (clothier) Mother's depression
- Robin Robarts Her father's suicide, John Robarts, Premier of Ontario 1961 – 1971 and her brother Tim's suicide
- Valerie Pringle (national television host) Her daughter's anxiety and panic attacks
- Amy Sky (singer/songwriter) post-partum depression

These stories lead the way for others to speak openly about their experiences with mental illness and are an important way to reduce stigma.

#### Recent Canadian event (March 2009)

Mastering mood disorders: Identifying and overcoming stigma and discrimination was a three-day event involving an initial day of consultation with consumers and families on their experiences of stigma and discrimination related to bipolar disorder. A second day convened the Collaborative RESearch Team – Bipolar disorder (CREST – BD) to exchange views on recent anti-stigma research and prepare proposals for review by CIHR. The third day was an accredited training for various professionals (mental health, physicians and other health professionals) as well as consumers and family members where strategies for fighting stigma and the links between uncovering stigma, self-management and recovery were examined. The joint sponsors of the event were CREST – BD and the Canadian Network for Mood and Anxiety Treatments (CANMAT) with funding from CIHR.

#### **International advances**

The National Institutes of Health in the United States has launched a call for research proposals (2008 – 2011) focusing on stigma and discrimination towards people with mental illness. In their call, they specify that successful applicants will demonstrate a partnership between stigma researchers and consumer groups and/or local agencies with hands-on experience. $^{41}$ 

http://www.ottawacitizen.com/Health/Lifting+mental+health+stigma/1246506/story.html

Full announcement available at: <a href="http://www.canada.com/edmontonjournal/story.html?id=3bec6cb6-5e3b-42e3-82f4-2e76ef70fdb3">http://www.canada.com/edmontonjournal/story.html?id=3bec6cb6-5e3b-42e3-82f4-2e76ef70fdb3</a>

<sup>&</sup>lt;sup>39</sup> For the full story, see:

<sup>40</sup> See: http://www.transforminglives.ca/

<sup>&</sup>lt;sup>41</sup> National Institutes of Health RO1 (call for proposals) (Jan 5<sup>th</sup> 2008). Reducing mental illness and discrimination. Available at: <a href="http://researchfunding.duke.edu/detail.asp?OppID=1919">http://researchfunding.duke.edu/detail.asp?OppID=1919</a> Mood Disorders Society of Canada (March 2009): Stigma research and anti-stigma programs: From the point of view of people who live with stigma and discrimination everyday.

New Zealand has recently (2007) extended for another five years its very successful Like Minds Like Mine anti-stigma and discrimination campaign. Over a previous 10 year period, the campaign has shown measurable results in changing attitudes and behaviours among New Zealanders.<sup>42</sup>

Australia has also extended its various anti-stigma plans and policies. For example, see Stepping Up: A Social Inclusion Action Plan for Mental Health Reform, 2007-2012, South Australian Social Inclusion Board. 43

MIND, an anti-stigma campaign in England, received 18 million pounds from a National Lottery grant.44

#### Recovery

Presently, the Mental Health Commission of Canada (February and March, 2009) is conducting nation-wide consultations on its National Mental Health Strategy using recovery as the foundational principle. In the background work for the 2006 MDSC stigma and discrimination workshop, we identified a recovery philosophy as the cornerstone of hope for people with mental illness. But more than that, recovery is a powerful antidote against self-stigma, the process by which people internalize the devaluing attitudes towards them and blame themselves for their illness. Recovery was the overarching principle upon which the workshop's findings rested and, now, it will become the lens through which the National Mental Health Strategy is developed.

#### What does all this mean?

For those of us who have a keen interest in national and provincial/territorial developments in the field of mental health - either as providers, consumers, families, advocates, researchers or policy makers – the increase in dialogue and activity around anti-stigma campaigns is seen as a victory. Finally, something is happening. However, there is a very long distance between research and operational plans and improving the day-to-day lives of Canadians struggling with mental illness.

The mental health literacy project (mentioned above) conducted a national survey of Canadians and found that, while most understood depression, they didn't think of it as a mental illness. Real mental illness, they believe, is rare. They were quick to recommend medical help but were suspicious of psychiatric medication as part of treatment – especially for what they thought of as milder mental illnesses (depression). They were optimistic about recovery for mild, but not serious mental illness. They also reported that they knew that stigma exists because they, themselves, would be wary about revealing that they had a mental illness. They expressed fears around dangerousness for those who had serious mental illnesses.

<sup>&</sup>lt;sup>42</sup> Like Minds, Like Mine National Plan 2007 – 2013: A programme to counter stigma and discrimination associated with mental illness. New Zealand's 10 year old anti-stigma program is extended. Available at: http://www.likeminds.org.nz/page/36-Like-Minds-National-Plans Website is available at: www.likeminds.org.nz

43 The plan is available at: http://www.socialinclusion.sa.gov.au/page.php?id=30

<sup>44</sup> As reported in: Martin. N. & Johnston, V. (2007). A time for action: Tackling stigma and discrimination. Available at: http://www.mentalhealthcommission.ca/English/Pages/AntiStigmaCampaign.aspx Mood Disorders Society of Canada (March 2009): Stigma research and anti-stigma programs: From the point of view of people who live with stigma and discrimination everyday.

Similarly, a University of Calgary study of depression literacy surveyed 3084 adult Albertans and found that many could recognize the symptoms of depression but 43.3% still felt that it was most likely caused by a weakness of character. 45

Further, the recent trial of Vincent Li (who murdered a fellow passenger on a bus in Manitoba) and his conviction of not criminally responsible (NCR) by virtue of a mental illness has brought out reporting that, in some instances, has been rampantly prejudiced against all people with mental illnesses. For example, a journalist writing in the National Post on February 17<sup>th</sup> 2009, equates mental illness with violence and accuses professionals and advocates of hiding the real picture by purposely misinterpreting statistics. 46 The case has also been the subject of a particularly virulent blog called "lunatics running the asylum called Canada."

On the international stage, the European Pact for Mental Health<sup>47</sup>has begun an antistigma campaign but with limited consumer and family involvement - despite the overwhelming research finding that a hallmark of successful campaigns must include consumers and families in all aspects.

And finally - and discouraging, the World Health Organization reports that, of all those with mental illness in the world, 75% never receive any treatment at all.<sup>48</sup>

#### **Conclusions and recommendations**

This is not the time to lose hope. We're on a long journey and, while it may seem never ending, recent activity in the area of anti-stigma and discrimination is unprecedented in Canadian history. It is also an activity that has shifted in tone.

Long ago efforts focused on imploring "normal" people to be kind and understanding of those who were afflicted with mental disorders. Present day initiatives involve consumers and family members and the central message is that there is no "us" and "them" – only a we. And **we** need to work together in order to achieve the changes we envision but are not yet experiencing. To that end, MDSC recommends:

#### Anti-stigma research

- Federal and provincial governments must model leadership in opposing stigma and discrimination towards those living with a mental illness. They must increase funding for mental health research, in general, and anti-stigma research (leading to action) in particular. They must also strengthen antidiscrimination laws and enforcement.
- Anti-stigma research must be tied to action. New methods (or under-utilized methods such as qualitative and participatory action research) must be embraced and funded.

<sup>&</sup>lt;sup>45</sup> Wang, Jian Li et al (2007). Depression literacy in Alberta: Findings from a general population sample. Canadian Journal of Psychiatry, vol 52, p 442 – 449.

Cosh, C. (Feb 17, 2009). Hiding the facts about mental illness. Available at: http://network.nationalpost.com/np/blogs/fullcomment/archive/2009/02/17/colby-cosh-hiding-the-factsabout-mental-illness.aspx

<sup>&</sup>lt;sup>47</sup> As reported in GAMIAN – Europe Newsletter, 10(31), Winter edition 2008/09.

Mood Disorders Society of Canada (March 2009): Stigma research and anti-stigma programs: From the point of view of people who live with stigma and discrimination everyday.

- Consumers and families must be an integral part of anti-stigma research, especially at the outset when questions are being formulated.
- Research findings must be disseminated in non-traditional ways so that
  consumers, families, and community agencies can make use of them.
  Researchers must stop talking only to themselves and engage with the people
  who are the subjects of their research and those who are supposed to be
  utilizing its findings.
- The Institute of Neurosciences, Mental Health and Addictions needs to move its anti-stigma research agenda forward, as a priority.

#### Health and mental health professionals

- Health and mental professions must confront the fact that stigma and discrimination towards people with mental illness is expressed, and expressed often, within their own ranks. Some professionals have taken leadership roles in this acknowledgement. Others have not yet done so. Acknowledgement is only a first step. Professional under- and post-graduation curricula must change, as must the commonplace tolerance of workplace expressions of stigma.
- Those involved in the provision of emergency department services must revise the Canadian Triage and Acuity Scale (CTAS) so that it is more effective in assessing psychiatric emergencies. These changes would go a long way in reducing wait times for those presenting with psychiatric difficulties in emergency rooms across the country.

#### Anti-stigma campaigns

- There is a need to conduct a Canadian environmental scan that documents all anti-stigma campaigns across the nation. These local activities will serve as a roadmap of innovation and best practice for others wanting to develop their own campaigns and, particularly, for the Mental Health Commission as it launches its own.
- The Mental Health Commission of Canada must continue to move quickly from planning to action, implementing its anti-stigma campaigns (based on best practices and including evaluation components) as soon as possible. It must reaffirm its commitment to involving consumers and family members in all aspects of these campaigns. Involvement does *not* mean simply presenting finalized plans or asking for approval of already-developed messages. It means that consumers and families lead MHCC campaigns and are part of all decision-making and implementation activities.

#### Recovery

Recovery philosophy is widely embraced but not widely practiced. Hope can
be a scarce commodity for those who work on the front lines and see exactly
how difficult life can be for people with mental illness, complicated by
poverty, violence, and ghettoized living conditions – to name only a few of the

indignities suffered. But the human spirit is courageous. This is well known by those of us who have recovered. We were there once, more down and out than can be imagined. But we made it and we have an obligation to help those who are still struggling. Recovery is not just a theoretical concept. Nor is it only to guide clinical work and medical intervention. It must also be the ever-present message when peer meets peer.

• In order to facilitate the recovery model, the medical system must become truly patient centred. To do this, it must recognize that psychosocial treatments are part of the continuum of care and become more collaborative in the provision of primary care by including the greater engagement of mental health professionals, peer support and self help. Medicine, psychiatry and all mental health professionals must more consistently include consumers - and their families (where appropriate) - in treatment decisions.

So, what progress have we made? Some, but not nearly enough.

#### Appendix 1

#### Examples of research into stigmatizing attitudes among mental health professionals

In a survey of 1073 mental health professionals and 1737 members of the general public, researchers found that psychiatrists held more negative attitudes toward people with mental illness than the general public. Mental health professionals of all types were three times more likely to support restrictions for people with mental illness than the general public. The authors concluded that better knowledge of mental illness did not reduce stereotyping nor did it enhance willingness to interact with people with mental illness.49

In another survey of 226 mental health professionals, it was found that they were less optimistic about long term outcomes for people with mental illness than the general public. Psychiatrists were the most pessimistic of all the professions surveyed, with nurses being less so. 50 These findings have been replicated. 51

In a study of 308 first and final year medical students regarding their attitudes towards psychiatric patients, it was found that final years students felt less fear, but were more indifferent and less compassionate when seeing patients with mental illness.<sup>52</sup>

In recent research, 50% of 567 psychiatrists surveyed by the Michigan Psychiatric Society said that they would treat themselves in secrecy rather than have mental illness recorded on their medical chart.<sup>53</sup>

An informal survey of 50 staff at Catawba Hospital in Virginia (a 110 bed state psychiatric facility) found that 60% of respondents said that, if they were diagnosed with schizophrenia, they would be uncomfortable talking to friends about their diagnosis.54

<sup>49</sup> Nordt, C. Rossler, W. & Lauber, C. (2006). Attitudes of mental health professionals toward people with schizophrenia and major depression. Schizophrenia Bulletin. 33 (4), p. 709 - 714. See: http://schizophreniabulletin.oxfordjournals.org/cgi/content/full/32/4/709

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health disorder. Journal of Psychiatric and Mental Health Nursing 8 (5), 419-425. For abstract, see: http://www.blackwell-synergy.com/doi/abs/10.1046/j.1351-0126.2001.00430.x?journalCode=jpm

The Mental health literacy in Canada: Phase 1 report (2007). Canadian Alliance on Mental Illness and Mental

Health. See: http://www.camimh.ca/files/literacy/MHL REPORT Phase One.pdf

<sup>&</sup>lt;sup>52</sup> Mistik, S, Turan, T. (2005). Changes in medical students' opinions and attitudes towards mental illness. Middle East Journal of Family Medicine, vol 3 (4). Available at: http://www.mejfm.com/journal/Sep05/Change in Medical Students.htm

<sup>&</sup>lt;sup>53</sup> Myers, M. (2001). Presidential address to the Canadian Psychiatric Association. New century: Overcoming stigma, respecting differences. Available at: http://www.cpaapc.org/publications/archives/CJP/2001/December/president.asp

54 Letter to the Editor from Thiru Sriram & Yad Jabbarpour (2005). Are mental health professionals

immune to stigmatizing beliefs? Psychiatric Services, vol 56, p. 610. Available At: http://psychservices.psychiatryonline.org/cgi/content/full/56/5/610

#### Appendix 2

## Eight research priorities agreed upon at MDSC's 2006 Stigma and Discrimination Workshop

1. What are the most effective strategies to reduce stigma and discrimination associated with mental illness and addiction across the life span among health and social service providers?

While MDSC acknowledges that it is hard for the helping professions to hear that they are among the most hurtful to consumers and survivors, the delegates spoke loudly and clearly – this is their number one priority.

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

This recommended research question speaks to another limitation of traditional research. Studies tend to examine programs that are affiliated with the universities where researchers work – academic health science centres and hospitals. While sticking to what is familiar is an undeniable human tendency, the result is that researchers neglect of a lot of promising activity. It is a tight-knit world where innovation is narrowly defined meaning that many programs never have the benefit of research, never enter the knowledge base, and thus, never become part of what is deemed to be "best practice."

3. What do mental health professionals do or do not do that consumers experience as stigmatizing and discriminatory?

So, out of the top three recommendations, consumers and families believe that research should focus on how the professionals – whom they turn to at a time when they are most in need – hurt them through negative beliefs, damaging attitudes and discriminatory acts.

Is anyone surprised? The professions are. Consumers and families are not.

4. What is the best way to teach children and youth about mental health issues using identified promising practices that reduce stigma?

If we reach the children, can we support the development of their own mental health and help them be kinder and gentler grown-ups who embrace all sorts of diversity more easily?

5. In what ways to children and youth (with mental illness and addiction) experience stigma and discrimination?

How can we help the kids? Adult consumers remember what it was like to be a kid and be different. It's not a positive experience.

6. What is needed to help service providers recognize and change their own stigmatizing and discriminatory attitudes and behaviours?

Once stigma and discrimination among the helping professions was clearly out in the open, delegates felt empowered to get more specific about what they wanted done – research, connected to action, that tackles real change.

7. What role does post-secondary education and health professional training play in perpetuating stigma and discrimination? What strategies might be effective in reducing stigma and discrimination among those training to enter the helping professions?

Here it is again. Delegates were thinking that maybe if we intervene when professionals are training, they will graduate with more open hearts and more respectful attitudes. After all, isn't that what helping is all about?

8. The final recommended question had to do with studying "contact strategies." Delegates asked, if direct, positive, personal contact with consumers and families really helps reduce stigma and discrimination, what can research tell us about the most effective way to go about it?

#### Appendix 3

## Examples of "grey literature" – reports and briefing papers Consumer blogs, writing

Canadian Mental Health Association, Ontario. Reports, papers and fact sheet about stigma and discrimination. Available at: <a href="http://miaw.ca/en/mental-illness/stigma-discrimination.aspx">http://miaw.ca/en/mental-illness/stigma-discrimination.aspx</a>

Canadian Mental Health Association, National (undated). Stigma and mental illness: A framework for action by the Canadian Mental health Association. Available at: <a href="http://www.cmha.ca/data/1/rec\_docs/1959">http://www.cmha.ca/data/1/rec\_docs/1959</a> Stigma.pdf

Health Scotland (2008). Stigma and discrimination: A guidebook for action. Available at: http://www.healthscotland.com/documents/2526.aspx

Health Scotland (2008). Stigma and discrimination: An international briefing paper. Available at: <a href="http://www.supportproject.eu/news/stigma/stigmatoolkit.htm">http://www.supportproject.eu/news/stigma/stigmatoolkit.htm</a>

HereToHelp: Stigma and discrimination around mental disorders and addiction (2006). Fact sheet. Available at:

http://www.heretohelp.bc.ca/publications/factsheets/stigma

Mental Illness Awareness Week (2008): Combating stigma and discrimination. See: <a href="http://miaw.ca/en/mental-illness/stigma-discrimination.aspx">http://miaw.ca/en/mental-illness/stigma-discrimination.aspx</a>

Stigma Busters Productions. Consumers mount plays such as *Bonkers* in the Ottawa area. See: http://www.stigmabusters.org/

Voices for Children Ontario (2006). Sticks and stones: breaking the stigma of child and youth mental health difficulties in schools. Available at: <a href="http://www.voicesforchildren.ca/reportindex.htm">http://www.voicesforchildren.ca/reportindex.htm</a>

Visions: Stigma and discrimination (2005) - a journal from HereToHelp BC: Information you can trust. Vol 2 (6). Available at: <a href="http://www.heretohelp.bc.ca/publications/visions/stigma-discrimination">http://www.heretohelp.bc.ca/publications/visions/stigma-discrimination</a>

#### Consumer blogs and writing

Deegan, P (undated). Recovery and the conspiracy of hope. Available at: http://www.namiscc.org/newsletters/February02/PatDeegan.htm

National Network for Mental Health, available at: <a href="http://www.nnmh.ca/">http://www.nnmh.ca/</a> Members write about experiences of stigma.

McManamy, J. Blog by journalist and individual with bipolar disorder. Clinicians: The worst purveyors of stigma? Available at:

http://knowledgeisnecessity.blogspot.com/2009/01/clinicians-worst-purveyors-of-stigma 05.html Also, Is bipolar cool? At:

http://knowledgeisnecessity.blogspot.com/2009/01/is-bipolar-cool.html

Tony's Schizophrenia Corner and Blog. Schizophrenia: Stigma and discrimination. Available at: <a href="http://tonysschizophreniacorner.blogspot.com/2007/06/schizophreniastigma-and-discrimination.html">http://tonysschizophreniacorner.blogspot.com/2007/06/schizophreniastigma-and-discrimination.html</a>