STIGMA: THE HIDDEN KILLER

Background Paper and Literature Review

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STIGMA: THE HIDDEN KILLER: Background Paper and Literature Review
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Executive Summary

People who live with mental illness and their families often state that the stigma associated with their diagnosis was more difficult to bear than the actual illness. Stigma is all-encompassing. It affects the ability to find housing and employment, enter higher education, obtain insurance, and get fair treatment in the criminal justice or child welfare systems. Stigma is not limited to the attitudes and actions of others. Self-stigma relates to internalized negative stereotypes that lead people with mental illness and their families to adopt attitudes of self-loathing and self-blame leading the a sense of helplessness and hopelessness.

Stigma is dangerous because it interferes with understanding, obtaining support from friends and family, and it delays getting help (sometimes for years). Stigma is:

- An inhibitor of primary prevention,
- A fundamental cause of disease (marginalization, oppression and denial of opportunity),
- A factor that limits early detection,
- A factor that interferes with positive treatment outcomes,
- A contributor to a drain on health resources and on the Canadian economy,
- An impediment to recovery,
- Multi-faceted and creates a multiplier effect (stigma piled upon stigma).

Theories about why people stigmatize involve ideas about humankind's natural protective responses to perceived threats and social processes that tend to identify and categorize human difference, leading to decisions regarding which individuals or groups are valued and which are not. The exercise of power is central to stigma - overtly to reject and exclude or covertly to devalue and discredit.

New directions for health-related stigma research suggest initiatives that document the burden of stigma, compare stigma among health problems, define the determinants of stigma, develop measurement tools and implement research methods that include consumers and families in research.

Consumers and families value research but tend to focus on research as it relates to action. Having experienced stigma first hand, they are interested in what, exactly, to do about it.

Research regarding anti-stigma interventions offers mixed results. Public attitudes and behaviours are extraordinarily resistant to change. In addition, most anti-stigma campaigns are un-evaluated, time-limited, piecemeal, depend on volunteers and are mounted with limited budgets. Some anti-stigma approaches that have potential:

Counteracting self-stigma

- Empowerment (self-help and peer support groups, economic development programs, Mad Pride parades, advocacy)
- Recovery (personal growth and healthier choices leading to improved quality of life)

Changing public attitudes

- Anti-stigma campaigns that involve positive contact with people with mental illness and their families (print ads, television, films, seminars and presentations),
- Media-watches to expose biased reporting or negative stereotyping,
- Laws and policies that prevent discrimination,
- Tests and surveys that encourage people to self-identify and get help,

- Self-expression through the arts which celebrate people's talents while, often, providing educational or advocacy messages.

This overview paper concludes with recommendations for future Canadian research directions that have particular resonance for consumers and families:

1. Self-stigma is the enemy within. It renders a person complicit with the injustice of externally imposed discrimination and stereotyping. Yet the processes by which people come to believe that they deserve ill-treatment and ostracism are ill defined. As result, mechanisms to counteract self-stigma are less well articulated. There is a rich source of ideas in the recovery movement that require further thought and, perhaps, re-framing in terms of the mechanisms that address the effects of self-stigma. Recovery, along with self-empowerment, may be among the premiere antidotes to self-stigma because they change one's own ideas about self and the world. **Self-stigma is an important area for further research.**

2. Anti-stigma campaigns are aimed at changing others' attitudes and beliefs. The sheer amount of activity offers many useful examples about what works, and what does not. In Canada, there is no need to re-invent the wheel. The time has come for action. Consumers and families are less concerned with measuring the extent and impact of stigma (they already know that). **Research attached to action would be highly valued.**

3. **Consumers and families must be involved**, not only in defining the actions to be taken and delivering the resulting campaigns, but also in the complete research process. They must participate in developing the research questions, collecting data and in analyzing results. No one cares more than they do about outcomes. As a result, they are the funders' best allies because they, too, want to ensure that investment pays off.

4. Often research, like many of the anti-stigma campaigns, can be piecemeal and unconnected. People don't hear about results and thus, are unable to make use of what has been learned. **Consumers and families have active organizations that can be utilized for the dissemination** of both the campaigns and the research findings.

Consumers and families recognize all too clearly that stigma can kill. They have a sense of urgency driven by personal experience that can be used to fuel change. However, changing attitudes and behaviours is extraordinarily difficult. While there is a lot of activity focused on anti-stigma campaigns and, while there is some evidence that beliefs are shifting, there is much work left to do.

Introduction

People who live with mental illness and their families often state that the stigma associated with their diagnosis was more difficult to bear than the actual illness. Stigma has a considerable influence on whether people seek treatment, take prescribed medications and follow through on treatment plans.[1] Consumers' and families' views of the pervasiveness of stigma have been confirmed through research. In a recent UK survey,[2] 70% of 556 respondents reported that either they or a family member had experienced stigma as a result of mental illness. Of those, 56% experienced stigma within their own family, 52% from friends, 44% from their primary care physician, 32% from other health care professionals and 30% within their workplace. In a Canadian survey of attitudes towards disabilities, respondents reported that, of all disabilities, they were the least comfortable when in the presence of someone with a mental illness.[3] These attitudes lead to discriminatory actions. Numerous surveys reviewed by a report on discrimination in British Columbia[4] showed that fully one-third to one-half of people have either been turned down for a job for which they were qualified or, if employed, been dismissed or forced to resign once it was known that they had a mental illness.

Stigma is all-encompassing. It affects the ability to find housing and employment, enter higher education, obtain insurance, and get fair treatment in the criminal justice or child welfare systems. People with mental illness also experience discrimination in the Canadian health care system. Their views are dismissed. They are ignored in emergency rooms and treated disrespectfully by family

[1] A Report on Mental Illnesses in Canada (2002). The Public Health Agency of Canada. Available at: http://www.phac-aspc.gc.ca/publicat/miic-mmac/

[2] Pull yourself together: A survey of peoples' experience of stigma and discrimination as a result of mental distress (2000). Mental Health Foundation, London, UK. Available at: http://www.mentalhealth.org.uk/page.cfm?pagecode=PBUP0204

[3] Canadian attitudes towards disability issues: 2004 benchmark survey. Social Development Council of Canada: Available at: http://www.sdc.gc.ca/asp/gateway.asp?hr=en/hip/odi/documents/attitudesPoll/index.shtml&hs=pyp

+[4] Discrimination against people with mental illness and their families: Changing attitudes, opening minds: A report of the BC Minister of Health's Advisory Council on Mental Health (April 2002). Available at: www.health.gov.bc.ca/mhd/ advisory/discrim_report_mar_apr_02.pdf -

physicians. Once known to have a mental illness, they report that their legitimate physical health concerns are disregarded. As a telling example of stigma among health care providers, 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.[5] Aside from the human cost, there is a general societal devaluing of mental health and mental illness resulting in less funding for research, treatments and services, and a low priority on the political and public policy agenda.[6]

Negative portrayals of mental illness in the media add to stigma

The stigma consumers and families experience is compounded by the powerful role the media play in depicting people with mental illness as dangerous and violent or alternatively simple, childlike and unable to care for themselves. Numerous studies canvassing media worldwide report consistent and disturbing results: People with mental illness are routinely negatively and inaccurately stereotyped.[7][8] For example, an analysis of American media found that mental illness was the most commonly depicted health problem, however, 72% of characters with mental illness either killed or injured someone.[9] The influence of

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[5] Myers, M. (2001). Presidential address to the Canadian Psychiatric Association. New century: Overcoming stigma, respecting differences. Available at: http://www.cpa-apc.org/publications/archives/CJP/2001/December/president.asp

[6] Understanding stigma about health (2003) The Pfizer Journal Special Edition: Health Repercussions of Stigma. Available at: http://thepfizerjournal.com/default.asp?a=article&j=tpj37&t=Understanding%20Stigma%20About%20Health&p=yes

[7] Francis, C., Pirkis, J., Dunt, D., & Blood, R. W. (2001). Mental health and illness in the media: A review of the literature. Canberra: Mental Health and Special Programs Branch, Department of Health and Aging, Australia. Available at: www.auseinet.com

[8] National Mental Health Association (2000). Stigma matters: Assessing the media's impact on public perception of mental illness, Chicago: National Mental Health Association. Available at: http://www.mindframe-media.info/mi/media.php

[9] Media images and messages about stigma: The good, the bad and the ugly (2003). The Pfizer Journal, Special Edition: health Repercussions of Stigma. Available at: http://www.thepfizerjournal.com/default.asp?a=article&j=tpj37&t=Media%20Images%20And%20Messages%20About%20Stigma

the media is such that it represents the *primary* source of information about mental illness for the general public.[10] Consumers report that these ubiquitous and misleading portraits further damage their mental health and self-esteem.[11] Inaccurate portrayals of symptoms and a general tone of hopelessness further contribute to misunderstanding and harm even when the media intend to be sympathetic.[12] Mental health professionals also, come in for their share of negative stereotyping with psychiatrist and therapists characterized as alternatively evil or bumbling.[13]

Self-stigma

Stigma is not limited to the attitudes and actions of others. People with mental illness have been exposed to the same social systems as those who discriminate against them. As a result, a particularly pernicious form of stigma relates to internalized negative stereotypes that lead to self-loathing and self-blame.[14] Fearing rejection, people with high levels of self-stigma are less likely to seek treatment in the first place or to participate once diagnosed. They also are less likely to apply for housing, seek employment or take positive actions that support their own health.[15] self-stigma means that people with mental illness and their families begin to expect poor treatment, devaluation and rejection from others and these beliefs can lead to feelings of helplessness and hopelessness.

Stigma defined by researchers

[10] Roth Edney, D. (2004). Mass media and mental illness: A literature review. Available at: http://www.ontario.cmha.ca/content/about_mental_illness/mass_media.asp
[11] Ferriman, A. (2000) The stigma of schizophrenia, British Medical Journal 320(7233), 522
[12] Wahl, O. (1995). Media madness: Public images of mental illness., New Brunswick, NJ: Rutgers University Press.
[13] Byrne, P. (2003). Psychiatry and the media. Advances in Psychiatric Treatment Vol 9 p. 135 – 143. Available at: http://apt.rcpsych.org/cgi/content/full/9/2/135
[14] Everett et al (2003). Recovery rediscovered: Implications for mental health in Canada. Available at: http://www.ontario.cmha.ca/content/mental_health_system/recovery.asp
[15] Watson, A. & Corrigan, P. (undated). The impact of stigma on service access and participation: A guideline developed for the Behavioural Health Recovery Project, Illinois Department of Human Services. Available at: www.bhrm.org/guidelines/stigma.pdf

Traditional definitions of stigma refer to an observable mark that identifies an individual for censure and condemnation, and sets him or her apart from others – the stigmata of Christ or the red letter "A" worn by Hester Prynne. In the 1960s, Ervin Goffman proposed a taxonomy of stigma with three dimensions: 1) physical deformity, 2) blemishes of character and 3) what he called tribal identities - social divisions related to race, gender, age, religion, ethnicity or sexual orientation. [16] However, identifying what is, or is not "normal" does not take into account cultural interpretations which can vary across nations and societies.[17] Also, these categories do not apply easily to health-related stigma[18] which has additional dimensions related to variables such as acute versus chronic, life-threatening versus a mild health problem, infectious versus non-infectious disease, unavoidable and blameless etiology versus behavioural and "your own fault," and easily treated versus no-known cure.

With these considerations in mind, authors in the area of health-related stigma have proposed the following definition – formed especially for the purposes of research:

> "Stigma is typically a social process, experienced or anticipated, characterized by exclusion, rejection, blame, or devaluation that results from experience or reasonable anticipation of an adverse social judgment about a person or group. This judgment is based on an enduring feature of identity conferred by a health problem or health-related condition, and the judgment is in some essential way medically unwarranted. In addition to

[16] Goffman, E. (1963). Stigma: Notes on the management of a spoiled identity. Engelwood Cliffs, NJ: Prentice-Hall Inc.
[17] Weiss, M. & Ramakrishna, J. (2004). Backgrounder paper: Health-related stigma: Rethinking concepts and interventions for the Research Workshop on Health-Related Stigma Conference, Amsterdam. Available at: http://www.kit.nl/frameset.asp?/development/html/products___services.asp&frnr=1&ItemID=2538
[18] Stigma is not exclusive to mental illness but occurs in relation to a number of health problems such as HIV/AIDS, TB, leprosy, incontinence, sexual dysfunction, obesity, obstetric fistula, epilepsy, substance abuse and SARS, as some examples.

its application to the persons or group, the discriminatory social judgment may also be applied to the disease or designated health problem itself with repercussions in social and health policy. Other forms of stigma, which result from adverse social judgments about enduring features of identity apart from health-related conditions (e.g. race, ethnicity, sexual preferences) may also affect health; these are also matters of interest that concern questions of health-related stigmas."[19]

Stigma defined by consumers and families

While researchers utilize models and theories to define stigma, consumers and family members take a different approach, informed by their own experiences of exclusion, rejection, blame and devaluation.

Patricia Deegan:

> "And then, at a time when we most needed to be near the one's we loved, we were taken away to far off places. At the age of 14 or 17 or 22 we were told that we had a disease that had no cure. We were told to take medications that made us slur and shake, that robbed our youthful bodies of energy and made us walk stiff like zombies. As these first winds of winter settled upon us we pulled the blankets up tight around our bodies but we did not sleep. During those first few nights in the hospital we lay awake. You see, at night the lights from the houses in the community shine through the windows of the mental institution. Life still went on out there while ours crumbled all about us. Those lights seemed very, very far away. The Zulu people have a word for our phrase "far away". In Zulu "far away" means, "There where someone cries out : 'Oh mother, I am lost." In time we did leave the hospital. We stood on the steps with our suitcases in

[19] Weiss, M. & Ramakrishna, J. (2004). Backgrounder paper: Health-related stigma: Rethinking concepts and interventions for the Research Workshop on Health-Related Stigma Conference, Amsterdam (p. 13). Available at: http://www.kit.nl/frameset.asp?/development/html/products___services.asp&frnr=1&ItemID=2538

hand. Most of us returned home and found that nothing was the same anymore. Our friends were frightened of us or were strangely absent. They were overly careful when near us. Our families were distraught and torn by guilt. They had not slept and their eyes were still swollen from the tears they cried. And we, we were exhausted. And now our winter deepened into a bone chilling cold. Something began to die in us. Something way down deep began to break. Slowly the messages of hopelessness and stigma which so permeated the places we received treatment, began to sink in. We slowly began to believe what was being said about us. We found ourselves undergoing that dehumanizing transformation from being a person to being an illness: "a schizophrenic", "a multiple", "a bi-polar." Our personhood and sense of self continued to atrophy as we were coached by professionals to learn to say, "I am a schizophrenic"; "I am a bi-polar"; "I am a multiple". And each time we repeated this dehumanizing litany our sense of being a person was diminished as "the disease" loomed as an all powerful "It", a wholly Other entity, an "in-itself" that we were taught we were powerless over. The weeks, the months or the years began to pass us by. Now our aging was no longer marked by the milestones of a year's accomplishments but rather by the numbing pain of successive failures. We tried and failed and tried and failed until it hurt too much to try anymore."[20]

Why stigma matters

Stigma is dangerous because it interferes with understanding, obtaining support from friends and family, and it delays getting help (sometimes for years). It can lead to:

- Denial of signs of mental illness in self

[20] Excerpts from Recovery and Conspiracy of Hope: A speech by Patricia Deegan (2002). Available at: http://www.namiscc.org/newsletters/February02/PatDeegan.htm

- Failure to recognize signs in others
- Secrecy and failure to seeking help
- Ostracism by one's friends, family and co-workers
- Self-blame
- Substance abuse or problem gambling to control symptoms
- Isolation
- Problems in relationships, school and work

In the extreme, it can lead to:

- Loss of career
- Family breakdown
- Suicide

The effects of stigma are far-reaching and costly, in human, social and economic terms. Researchers have paid considerable attention to measuring and reporting on its impact (see **Appendix 1** for a listing of measurement tools).

Stigma as an inhibitor of primary prevention: Access to health determinants (housing, education, employment, income and social support) are limited by stigma. People who are isolated from mainstream society have a much more difficult time competing for basic life chances. They are exposed to numerous health risks (poor nutrition, fetal alcohol syndrome and other birth defects, smoking, drugs and obesity), live in unsafe conditions where violence is a threat (guns, racism, crime, domestic violence and child abuse), and cope with multiple losses (children to state welfare, spouses to the criminal justice system and friends and family to suicide).[21]

[21] Link, B. & Phelan, J. (2001). On stigma and its public health implications. Available at: www.stigmaconference.nih.gov/LinkPaper.htm

Stigma as a fundamental cause of disease: People who are marginalized and oppressed are under great strain. The stress of striving but not succeeding, of having fewer opportunities or of being targeted by mainstream society through stereotypical media portrayals or constant police attention takes its toll on both physical and mental health.[22] Denial of opportunity often leads to poverty and poverty is the single most accurate and stable predictor of ill health, regardless of time or place.[23]

Stigma as preventing early detection: Shame and secrecy leads people to conceal or deny distress, to the point that they do not ask for help and end up with more chronic forms of illness.[24] For example, it is estimated that two out of three people with a diagnosable mental illness do not seek treatment.[25] In addition, primary care providers do not routinely ask about symptoms related to mental illness yet there are specific guidelines published by their Colleges regarding primary prevention testing such as mammograms, PSA tests or tests for serum levels of cholesterol.

Stigma as affecting treatment outcomes: Mental illness, as it presents itself in the health provider's office, may come in disguised forms (poor sleep, persistent but vague physical complaints or lack of energy), leaving health providers bewildered as to what exactly is wrong. People may resist taking psychiatric medications that could help because they are embarrassed to have their prescriptions filled.[26] They may avoid therapy (if it is available at all) because it is only for people who are "screwed up" – and therefore not for them. Treatment conditions may be

[22] Link, B. & Phelan, J. (2006). Stigma and its public health implications. The Lancet. 367(9509), p. 528 – 529. Available at: www.thelancet.com
[23] Link, B. & Phelan, J. (2001). On stigma and its public health implications. Available at: www.stigmaconference.nih.gov/LinkPaper.htm
[24] Davis, S. (2006). Community mental health in Canada. Vancouver, BC: University of British Columbia Press.
[25] A Report on Mental Illnesses in Canada (2002). The Public Health Agency of Canada. Available at: http://www.phac-aspc.gc.ca/publicat/miic-mmac/
[26] Sirey, JA. et al (2001). Perceived stigma and patient-related severity of illness as predictors of anti-depressant adherence. Psychiatric Services. 52, p. 1615 – 1620. Available at: http://ps.psychiatryonline.org/cgi/content/abstract/52/12/1615

overly harsh in response to society's desire to rid itself of the perceived threat of violence or contamination. Institutional psychiatric treatment includes locked wards, restraints, searches, and seclusion. Investment in improving treatment or expanding research is in short supply, meaning that scientific advances are slow to reveal themselves. As a result of limited attention for the issue of mental illness, patients, families, researchers and providers are forced to make do with poor prognoses, predictions of chronicity and limited hope.[27]

Stigma as an economic drain on health resources and on the Canadian economy: Mental disorders contribute more to the global burden of disease than all cancers combined.[28] The most common cause of violent death in the world is suicide.[29] In Canada, the fastest growing cost sector for occupational disability is psychiatric disorders. The Canadian economy annually loses $14.4 billion due to mental illness and $18.6 billion due to substance abuse in the workplace. It is also estimated that Canadians pay an additional $278 million in fees to psychologists and social workers in private practice. [30]

Stigma as an impediment to recovery: Stigma implies permanency – people have entered a social category from which there is believed to be no exit. Consumers report that their advocacy is often disregarded because, if they stand up for their rights and speak with clarity and purpose, then by definition, they can't have been ill in the first place.[31] Self-stigma also contributes to the denial of recovery

[27] Link, B. & Phelan, J. (2001). On stigma and its public health implications. Available at: www.stigmaconference.nih.gov/LinkPaper.htm
[28] Murray, C. Lopez, A. (1996). The global burden of disease: A comprehensive assessment of mortality and disability from diseases, injuries and risk factors in 1990 and projected to 2020. Cambridge, MA: Harvard University Press.
[29] World Health Organization: Report on violence and health, Geneva (Oct 2002). Table 1.2 p. 10 as quoted in Kirby, M. & Keon, W. (2004). Report 1, Mental health, mental illness and addiction: Overview of policies and programs in Canada (Chapter 5). Interim report of the Standing Senate Committee on Social Affairs, Science and Technology.
[30] Stephens, T & Joubert, N. (2001). The economic burden of mental health problems in Canada. In Chronic Diseases in Canada, 22 (1). Available at: www.phac-aspc.gc
[31] Everett, B. (2000). A fragile revolution: Consumers and psychiatric survivors confront the power of the mental health system. Newbury Park, CA: Sage Publications.

because people with mental illness believe the messages of helplessness and hopelessness and give up on themselves and their futures.[32]

Stigma as a multiplier effect: Stigma comes in multiple forms and can relate not only to health conditions such as mental illness but also to gender, age, race, ethnicity and other forms of categorizations that mainstream society define as "tainted."[33] Stigmatization piled upon stigmatization has an overwhelming negative effect on identity, self-esteem and access to opportunity. Members of stigmatized groups can become labeled as disease carriers, themselves, and shunned because they are believed to be fundamentally contaminated. In the present day, advances in genetic research add further concerns. People may be stigmatized as early as in utero because their genetic make-up may be thought to pre-dispose them to certain illnesses or anti-social behaviours.[34]

Attempts to rename stigma

Some authors have tried to find another term for stigma, one which clearly embodies the hurt it causes along with a message that marginalization and oppression, based on the presence of a mental illness, will not be tolerated.

Psychophobia: Peter Byrne (University College of London)[35] suggested the term psychophobia because there is no word for prejudice against mental illness. Using examples such as racism, ageism and sexism, this author argues that finding and applying an "ism" to describe unfair treatment for people with mental illness is the first step in combating stigma. However, psychophobia has not entered mainstream language.

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[32] Perlick, D. (2001) Special section on stigma as a barrier to recovery Psychiatric Services 52(12). Available at: http://ps.psychiatryonline.org/cgi/content/full/52/12/1613
[33] Wailoo, K. (2006). Stigma, race and disease in 20th century America. The Lancet, 367(9509), p. 531 – 533. Available at: www.thelancet.com.
[34] Keusch, G. Wilenz, J. & Kleinman, A. (2006). Stigma and global health: Developing a research agenda. The Lancet, 367(9509), p. 525 – 527. Available at: www.thelancet.com.
[35] Byrne, P. (2003). Psychiatry and the media. Advances in Psychiatric Treatment Vol 9 p. 135 – 143. Available at: http://apt.rcpsych.org/cgi/content/full/9/2/135

Healthism: Healthism is the term introduced in a special edition of the Pfizer Journal (2003) dedicated to the issue of stigma. Journal editor, Salvatore Giorgianni, agued in favour of this new word to embody the prejudice that is inherent in health-related stigma.[36] There is no evidence that healthism, as a substitute for stigma, has caught on.

Discrimination: Discrimination describes sets of activities based on false beliefs that seek to exclude stigmatized persons or groups from life's opportunities. Consumers and family members and some researchers and authors prefer the term discrimination to that of stigma because it points to action, whether it is anti-discrimination policies and laws, or human rights legislation.[37]

Back to stigma: Others argue that stigma is a much larger idea than discrimination because it refers to inaction and neglect, not just overt exclusion. It also allows for a discussion of prejudicial attitudes (both pubic and personal) that may be disguised as kindness or concern (for example, over-protection or communicating low expectations) but which are, in fact, expressions of stigma. Policies can change at will, but it is much more difficult to change attitudes. The term stigma is thought to encompass the whole picture of overt and covert exclusion.[38]

Models and theories regarding why people stigmatize

[36] Giorgianni, S. (2003). Stigma, health and communication. The Pfizer Journal. Available at: http://www.thepfizerjournal.com/default.asp?a=article&j=tpj37&t=Stigma%2C%20Health%2C%20and%20Communication

[37] Everett, B. (2004). Best practices in the workplace: An area of expanded research. HealthCarePapers. Vol 5(2). Available at: http://longwoods.com/product.php?productid=16831&cat=350&page=1

[38] Roundtable Seven: Stigma, discrimination, myths and public awareness (May 14th, 2003). Report on discussions available at: www.cpa-apc.org/Government/RondtableSevenSummary_DV1.pdf

Some theories of why stigma exists refer to the evolution of humankind whereby the survival of individuals and groups mean that they were attuned to threat. Threats (perceived or real) are accompanied by emotional responses that may include fear or disgust. Today, humans retain this innate response which may apply not only in times of threat, but also in the face of difference or that which seen to be unfamiliar. These latter associations are thought to be learned, offering optimism for anti-stigma interventions because that which is learned can also be unlearned.[39]

As a result of investigations into health-related stigma, other theories regarding why people stigmatize have come to include social and psychological dimensions. For example, one focus has been on the social process of stigmatization where researchers propose five components:

1. People naturally identify and categorize human difference – this, in itself, is benign. However, they also…
2. Decide which differences are valued and which are not.
3. Link the perception of difference to a set of undesirable characteristics – the process of stereotyping.
4. Separate "us" from "them." In health-related stigma, this is often accomplished by blame.. you brought this on yourself.. if you just tried harder you could shake it.. this is malingering…
5. Exercise power to reject, exclude and attack the credibility of the stigmatized person.[40]

Another approach to understanding stigma is defining the individual's lived experience: *Perceived* (fears about what *might* happen if the secret is known),

[39] Schaller, M. & Neuberg, S. (undated). The nature in prejudice. Available at: www.psych.ubc.ca/~schaller/SchallerNeuberg.doc
[40] Link, B. & Phelan, J. (2006). Stigma and its public health implications. The Lancet, 367(9509), 528-529. Available at: www.thelancet.com

experienced (discrimination, denial of rights, ostracism, or loss of employment) and *internalized* (shame, guilt and self-blaming).[41]

And there are additional considerations, particularly with health-related stigma. Medical labeling can take over identity. People become known as "a schizophrenic" rather than a person who has schizophrenia. There can also be a perception that the person *prefers* to suffer – otherwise why don't they just get better?[42] Some of the worse offenders in perpetuating stigma are health professionals, themselves, particularly in the area of mental health.[43] Psychiatry has a history of lending itself to activities that have perpetuated stigma and discrimination. For example, psychiatry played a prominent role in the eugenics movement, forced sterilization, controlling immigration, incarcerating political dissenters in psychiatric hospitals and in screening and labeling military personnel for mental instability.[44] One author points to a "history of dumb ideas in psychiatry" which includes theories that mental illness was created by lunar cycles, diseases of the womb or "schizophrenogenic" mothers, so-called treatments such as beatings and confinement to correct bad behaviour, insulin shock treatments, frontal lobotomies and treatments for the "disease" of homosexuality.[45] These ideas were not just dumb. They were harmful.

Graham Scrambler (University College of London) proposes a jigsaw model of health-related stigma which involves a perceived deficit as defined by a myriad of social forces (political, medical, national, or religious – as only some examples)

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[41] Findings: Research workshop on health-related stigma and discrimination (2004). Amsterdam. Available at: http://www.stigmaconference.nih.gov/WeissPaper.htm
[42] Media images and messages about stigma: The good, the bad and the ugly (2003). The Pfizer Journal Special Edition: Health Repercussions of Stigma. Available at: http://www.thepfizerjournal.com/default.asp?a=article&j=tpj37&t=Media%20Images%20And%20Messages%20About%20Stigma
[43] Kirby, M. & Keon, W. (2004). Report 1, *Mental health, mental illness and addiction: Overview of policies and programs in Canada*. Interim report of the Standing Committee on Social affairs, Science and Technology. Quote from Jennifer Chambers' testimony.
[44] Sayce, L. (2000). From psychiatric patient to citizen: Overcoming discrimination and social exclusion. Basingstoke, UK: Macmillan.
[45] Byrne, P. (2000). Stigma of mental illness and ways of diminishing it. Advances in Psychiatric Treatment, Vol 6, p. 65 – 72. Available at: http://apt.rcpsych.org/cgi/content/full/6/1/65

combined with the notion of culpability – you brought this on yourself. He also argues that those who are stigmatized are subjected to the twin forces of exploitation and oppression.[46] In building a model of stigma, attendees at the recent Research Workshop on Health-Related Stigma (Amsterdam, 2004), argued that stigma exists when any two of the three proposed dimensions intersect: social exclusion, disadvantage and low value/ low self-worth.

Finally, in examining workplace stigma related to mental illness, Canadian researchers argue that the conditions that support stigma are:[47]

1. The underlying erroneous assumptions about mental illness and the mentally ill that are held in general society
2. The intensity of these false beliefs – are they firmly and emotionally held and unlikely to change through education or are they a result of lack of knowledge?
3. These false beliefs are held by key people in positions of decision-making and power,
4. The presence of enabling factors such as no clear policies for accommodation, an atmosphere of devaluation of difference in the workplace or poor management practices.

New directions in stigma research

The Institute of Neurosciences, Mental Health and Addiction recognized stigma as a key problem in its inaugural strategic plan. It also has held two New Emerging grants competitions for mental health and addiction focused on the issue of stigma.

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[46] Ibid

[47] Krupa, T. Kirsh, B. Cockburn, L. & Gerwurtz, R. (June 2, 3 - 2005). Development of a model of stigma of mental illness in the workplace. Presentation to Workplace Mental Health Research: A Platform for Research Conference, Montreal. Available at: http://www.inspq.qc.ca/santementaletravail/presentationsEN.asp?P=10

In two recent international conferences,[48] researchers gathered to develop a shared agenda for stigma research. (See **Appendix 2** for a listing of conferences both past and pending, as well as organizations, journals, reports and books focused on the issue of stigma.)

Stigma and Global Health: Developing a Research Agenda (2001) held in Bethesda, Maryland: This conference focused on stigma as a public health issue. Proposed research questions that were considered priorities for attendees to consider were:[49]

1. Document the burden of stigma as it relates to various health problems.
2. Compare stigma for different health problems in different contexts.
3. Identify the determinants of stigma and the impact of stigma on health policy priorities.
4. Evaluate changes in the magnitude and character of stigma overtime in response to interventions and social changes.
5. Specify background information about diseases so that laws and health policy have the information required to minimize stigma.
6. Investigate methodologies to craft clear, compelling messages for the public without getting bogged down in the complexities of stigma-reducing strategies.

As a result of the findings at this conference, the Fogarty International Centre (FIC) announced a new research program to support international research on stigma and health. The commitment was to grant $11 million over five years in

[48] *Stigma and Global Health: Developing a Research Agenda.* Held in Bethesda Maryland in September 2001. Sponsored by the Fogarty International Centre. http://www.stigmaconference.nih.gov/ and,
Health-related Stigma and Discrimination: Rethinking Concepts and Interventions. http://www.kit.nl/frameset.asp?/development/html/products___services.asp&frnr=1&ItemID=2538 Conference held in *December 2004* in Soesterber, The Netherlands, sponsored by the Royal Tropical Institute (KIT).

[49] Weiss, M. & Ramakrishna, J. (2001). Interventions: research on reducing stigma. Available at: www.stigmaconference.nih.gov/WeissPaper.htm

response to investigator proposals. The focus of the research is national, international and cross-cultural research relevant to global health. Mental illness was one eligible area for research along with HIV/AIDS, tuberculosis, epilepsy, substance abuse and Parkinson's disease. The Institute of Neurosciences, Mental Health and Addiction participated by co-funding a Canada – United States research team.

Health-related Stigma and Discrimination: Rethinking Concepts and Interventions (2004) held in The Netherlands: Attendees looked at models of stigma, measurement tools, stigma reduction interventions and areas for future research. Recommendations were:

1. Researchers need to address health-related stigma in multiple conditions and collaborate across diseases, programs and disciplines.
2. There is a need to demonstrate links between stigma reduction and health outcomes or quality of life.
3. Research must be framed in a way that it is relevant to funders and decision- and policy-makers.
4. Develop a single basic quantitative measure that is applicable and validated across wide-ranging contexts and conditions.
5. Involve the people who are suffering from various stigmatized conditions in all stages of stigma research.

The result of the conference was the establishment of the International Consortium for Research and Action Against health-related Stigma (ICRAAS) at www.dgroups.org/groups/Stigmaconsortium

What to do about stigma?

Consumers and families value research but also have a heightened sense of urgency and prefer a focus on research specifically as it is tied to action. Having

experienced stigma first hand, they are interested in what, exactly, to do about it. The theories about what people stigmatize help point to effective interventions.

Self-stigma

Empowerment strategies work in reducing self-stigma.[50] Forms of empowerment are protests and parades (anti-psychiatry advocacy or Mad Pride parades, for example), economic development projects that offer employment and income, belonging to a family self-help group,[51] or becoming involved in consumer peer support where, in both cases, people are free to talk openly among themselves away from negative social judgments.[52] Members of these groups exchange coping strategies,[53] provide tips and offer one another emotional support. Some groups branch out into educational and advocacy activities. The clear message, "you are not alone," appears to reduce self-stigma and empowers people on a number of levels, not the least of which is dealing more effectively with externally-imposed stigma. People recognize that, with the power of the group behind them, there are ways of taking effective action.

Recovery is a process of living well despite challenges. It is an individual journey characterized by personal growth, empowerment, better management of troubling symptoms and healthier choices, thereby improving one's quality of

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[50] Researchers have looked into what consumers and families have tried, on their own, to avoid or reduce the stigma they experience. Coping strategies such as trying to keep their history of treatment a secret, isolating so as to avoid rejection and educating others about their diagnosis so that they can understand better and therefore be more sympathetic did not work, and, in fact, were harmful. Link, B. Mirotznik, J & Cullen, F. (1991). The effectiveness of stigma coping orientations: Can negative consequences of mental illness labelling be avoided. Journal of Health and Social Behavior. 32(3), p. 302 – 320. Abstract available at: http://www.ncbi.nlm.nih.gov/entrez/query.fcgi?cmd=retrieve&db=pubmed&list_uids=1940212&dopt=Abstract

[51] Boydell, K. Jadaa, D. & Trainor, J. (under review). A saving grace: Self-help for families of people with serious mental illness. Available from Dr. Katherine Boydell c/o Hospital for Sick Children, Toronto ON.

[52] Nelson, G. (2004). What was learned about members of CSIs in Making a Difference. Available through the Centre for Addiction and Mental Health, Toronto ON.

[53] Corrigan, P. (2001). Don't call me nuts: Coping with stigma and mental illness. Tinley Park, Ill: Recovery Press.

life.[54] As people take control of their lives, they build self-esteem and reject internalized negative stereotypes. They also gain the confidence to confront or counteract others' attitudes and discriminatory behaviours. Recovery does not make the world a fairer place to live, but it changes how people see themselves in relation to inequity so they can more effectively argue for their rights.

Anti-stigma campaigns and strategies

People with mental illness, families, providers and policy makers have struggled with the question of how to reduce and eliminate stigma in society. There are five conceptual approaches that seek to counteract stigma with an alternative argument:[55]

1. It's a brain disease. - This strategy is referred to the no-fault model but it has at least two draw backs. First, people may simply not believe the basic premise and second, it may invite over-protectiveness and paternalism which are also expressions of stigma.

2. The individual growth model – mental health and illness exist on a continuum and can occur at any time in the life cycle. The concern with this approach is that it doesn't address the "us" and "them" dichotomy. "We" have mild depression, while "they" have real mental illness – schizophrenia for example.

3. Libertarian model – The myth of mental illness, as argued by Thomas Szasz[56] calls for no special treatment for people with mental illness

[54] Copeland, M. A. Wellness Recovery Action Plan (WRAP) Program. Available at: http://www.copelandcenter.com/whatiswrap.html
[55] Sayce, L. (2000). From psychiatric patient to citizen: Overcoming discrimination and social exclusion. Basingstoke, UK: Macmillan.
[56] See http://www.szasz.com/szaszwri.html for a listing and examples of writings by Thomas Szasz.

whether through disability allowances or in the criminal courts. We are all equal.

4. Disability inclusion model – This approach makes a civil rights-based case People with mental illness are entitled to the same rights, freedoms and responsibilities accorded all citizens.

5. Social inclusion: This strategy argues that difference, as embodied by mental illness, is just another expression of diversity and must be respected as such.[57]

Combating stigma is complicated.[58] Over the years, there has been a developed wisdom about health-related stigma and the efforts that do, [59] and do not work when seeking to eliminate it. See **Appendix 3** for some approaches that have *not worked.*

Anti-stigma campaigns

While there is a substantial body of research that defines the extent and impact of stigma in society, there is little study of what works to combat it. However, there are three strategies that have received attention in the literature.[60]

[57] Bryne, P. (2003). Stigma, discrimination or social exclusion? Plenary session: Reducing stigma and discrimination: What works? Rethink Conference, Birmingham, England.
[58] Corrigan, P (ED) (2005). On the stigma of mental illness: Practical strategies for research and social change. Washington: American Psychological Association.

[59] Reducing stigma and discrimination: What works? (June, 2003) Showcasing examples of best practice of anti-discrimination projects in mental health. Conference report: Rethink / Institute of Psychiatry conference held in Birmingham, England. Available at: http://www.iop.kcl.ac.uk/iopweb/departments/home/default.aspx?locator=461

[60] Van der Meij, S. & Heijnders, M. (2004). The fight against stigma: Stigma reduction strategies and interventions. A paper prepared for the research Workshop on Health-Related Stigma, Amsterdam. Available at: http://www.kit.nl/frameset.asp?/development/html/products___services.asp&frnr=1&ItemID=2538

Protest: Activities include advocacy, Mad Pride parades, ECT protests and consumer or family empowerment groups. Messages are most often focused on exposing what are believed to be the harms associated with psychiatric treatment, disseminating the real facts about mental illness and counteracting negative stereotypes. The limited research available shows that these forms of protest do not seem to have a lasting impact on changing attitudes in the general public. Negative attitudes remain much the same but go underground and are not expressed as openly. Authors conclude that protest is an entirely legitimate activity with great utility – but not in reducing stigmatizing attitudes in the general public. However, as discussed above, consumers and families report that these activities help reduce self-stigma and, as a result, are highly valued as a form of empowerment and a step in recovery. [61]

Education: Activities include class presentations, films, and speeches – with a specific audience in mind. Again, education is a worthwhile and valuable intervention but research shows that new understandings do not necessarily lead to attitude and behavioural change.[62]

Contact: This activity involves face-to-face positive interactions with persons who have mental illness. Research shows contact to be associated with improved attitudes but it must be noted that the site of study[63] has most often been in teaching environments where students receive lectures and seminars from people with mental illness as part of their training. In further research that evaluated a video (made by consumers and featuring their stories) shown to high school students, it was found that, when only the video was presented, negative

[61] See the WRAP program. Available at: www.mentalhealthrecovery.com

[62] Penn, D. Kommana, S. Mansfield, M. & Link, B. (1999). Dispelling the stigma of schizophrenia: The impact of information on dangerousness. Schizophrenia Bulletin 25(3) p. 437 – 446. Abstract available at: http://www.ncbi.nlm.nih.gov/entrez/query.fcgi?cmd=retrieve&db=pubmed&list_uids=10478779&dopt=Abstract

[63] Van der Meij, S. & Heijnders, M. (2004). The fight against stigma: Stigma reduction strategies and interventions. A paper prepared for the research Workshop on Health-Related Stigma, Amsterdam. Available at: http://www.kit.nl/frameset.asp?/development/html/products___services.asp&frnr=1&ItemID=2538

beliefs and fears of dangerousness actually increased. When it was accompanied by a discussion led by one of the subjects of the video, it was found that stigma was reduced.[64]

Changing attitudes and behaviour have proved to be extraordinarily difficult. Heather Stuart (Queens University) reviewed Canada's anti-stigma history.[65] Initial activity began in the 1950s in a small Saskatchewan town using an intensive, multi-pronged approach (radio, discussion groups, educational materials, and films). The community did not change attitudes or behaviour and, in fact, retaliated against the study team by shunning them. Twenty-three years later, another researcher[66] visited the same community and using the same survey materials found that not much had changed. Over twenty years, studies in Winnipeg[67] showed very little shift in attitudes although direct, personal contact (as discussed above) had a demonstrated effect. In the 1990s, work in Alberta showed that people now had a greater knowledge of mental illness but still held negative attitudes. In fact, staff working in mental health agencies were as stigmatizing as the general population. Stuart offers ten lessons:

1. Improve the quality of life for people with mental illness. Trying to educate the public does not make the community more welcoming.
2. Involve consumers and families in all aspects of programs and services so the most important expressions of stigma are addressed.
3. Education does not change behaviour and real change occurs only when behaviour changes.
4. Modest, targeted programs that can deliver complex and emotional messages to small audiences have the best chance of succeeding.
5. There is no such thing as a general population. Target your audience.

[64] Tolomiczenko, G. Goering, P. & Durbin, J. (2001). Educating the public about mental illness and homelessness: A cautionary note. Canadian Journal of Psychiatry. 46, p. 253 – 257.
[65] Stuart, H. (2005). Fighting Stigma and discrimination is fighting for mental health. Canadian Public Policy Special Electronic Supplement: Mental health reform in the 21st century. Available at: http://economics.ca/cgi/jab?journal=cpp&view=v31s1/CPPv31s1p021.pdf
[66] ibid
[67] ibid

6. Start locally.
7. Accumulate small successes.
8. Use media as allies, rather than objects of intervention. (Note that most examples of anti-stigma campaigns do not agree and consider a media watch as central to their efforts.)
9. Build on others' work
10. Evaluate what you do and tell others about it.

Other types of useful anti-stigma approaches

Media-watches: Given the power of the media, one of the most popular anti-stigma approaches are campaigns that identify and protest against news reporting, films or television programs that propound negative stereotypes. For example, StigmaBusters (NAMI) publishes stigma alerts and will mount a national campaign in circumstances where the offense is considered egregious (for example, the Jim Carrey movie, Me, Myself, and Irene). It also compliments reporters and film-makers when they are accurate in their portrayals (Monk, As Good as it Gets, A Beautiful Mind). Other groups publish guides for journalists on acceptable language and reporting approaches.[68] [69] And finally, there have been reports on media activities in the wake of particularly glaring and offensive reporting.[70]

The law: The law is a limited resource for reducing stigma but it has certain utility.[71] For example, laws can protect the privacy of personal health information. They can deter discrimination and specify penalties for those that trample upon

[68] Mindshift: A guide to open-minded media coverage of mental health. Available at: http://mindout.clarity.uk.net/p/p03-media.asp
[69] Mindframe media guide (Australia). Available at: http://www.mindframe-media.info/about/index.php
[70] Mind over Matter: Improving media reporting of mental health (2006). Available at: http://www.shift.org.uk/mindovermatter.html published in the wake of an outcry in Britain when a newspaper headline reported "Bonkers Bruno Locked Up" – referring to the mental health problems of former heavyweight champion Frank Bruno.
[71] Burris, S. (2006). Stigma and the law. The Lancet. 367 (9509), p. 529 – 531. Available at: www.thelancet.com.

people's civil and human rights. Laws can also provide compensation for wrongs done to individuals through acts of discrimination. The enactment of civil and human rights codes that include deterrents for discrimination based on a person's health condition (including mental health) are important but they do not change attitudes and only offer narrow protection. For example, an employer cannot fire someone because they have a mental illness but customers can refuse to buy from them. No law prevents ostracism by family members or rejection from friends. In addition, the protective laws that do exist place the onus on individuals to complain and then work their way through complicated complaints procedures and hearings. Many people simply do not have the skills or the fortitude to demand recompense or retribution for the discrimination they have faced.

Tests and surveys aimed at self-identification: While not a traditional anti-stigma strategy, many organizations are publishing self-assessment questionnaires that help people understand that what they are experiencing may be a mental illness and, hopefully, reach out for help. For example, National Depression Day Screening held every October since 1991 in Canada and the United States allows people to test themselves, in person with a health care professional or online. It tests not only for depression, but also bi-polar disorder, post traumatic stress disorder, eating disorders, substance abuse and suicidal ideation. [72] Recently announced, Check up from the Neck up is an online test that allows people to test themselves for a variety of mood disorders.[73]The publicity that surrounds these efforts brings the issues of mental illness to wider attention. It also offers a private means of assessing symptoms and access to quality information about mental illness so that people can approach their health care provider armed with knowledge right from the outset. The ability to take a more empowered stance in the helping relationship can go a long way to counteracting

[72] See http://www.mentalhealthscreening.org/
[73] See http://www.checkupfromtheneckup.ca/

self-stigma and it leaves self-esteem much more intact so that people have an increased ability to resist hurtful attitudes and actions from others.

The arts: Art, in all its forms, has long been used as a form of therapy for people with mental illness. But consumers and families have taken their desire for personal expression much farther. They have developed film festivals, plays, poetry, sculpture and art shows, all open to the public. These efforts not only showcase their talents and provide income, but also present their advocacy messages in entertaining and compelling ways. While not strictly anti-stigma campaigns, these endeavors counter self-stigma through supporting positive self-expression and address externally exposed stigma through their public visibility.

Current anti-stigma activity

> See **Appendix 4** for a full listing of anti-stigma campaigns in Canada, the UK, Australia, the United States and a fuller description of the New Zealand campaign outlined below. This appendix also describes the world-wide campaign, Open the Doors, sponsored by the World Psychiatric Association.

Despite negative results regarding the effectiveness of anti-stigma campaigns, there are dozens of public education activities underway in Canada, the United States, Australia,[74] New Zealand and the United Kingdom. Many adopt multiple approaches which may include public service announcements, how-to pamphlets that encourage local communities to participate, speakers' bureaus, media

[74] In April 2006**,** The Australian government announced an investment of $1.8 billion in new funds for mental health in that country. As part if that announcement, new programs will be created to increase community awareness of mental illness particularly in relation to the connection between dug abuse and subsequent mental health problems. Announcement available at: http://www.aushealthcare.com.au/documents/news/6994/Howard%20050406.pdf

watches, policy and advocacy papers and educational seminars for the general public and health professionals in training. Some utilize World Mental Health Day (October 10th 2006) as a focus for their activities. However, most are time-limited, not be well funded and depend only on volunteers to bring them to life. Many have no evaluation mechanisms and there is little coordination among efforts.

In Canada, there are two weeks annually dedicated to publicizing issues related to mental health and mental illness (Mental Health Week, May 1 – 7th 2006 and Mental Illness Awareness Week, October 1 – 7th 2006). These weeks tend to focus anti-stigma efforts. The Canadian Mental Health Association's present campaign offers the message, "It's OK to look after your body. Just don't forget about your mind." The Canadian Psychiatric Research Foundation also has a national campaign called Imagine. It features ads that state, "Heart disease. Just another excuse for lazy people not to work" or "Wheelchair access? Can't those people learn to help themselves?" with the following message, "Imagine if we treated everyone like we treat the mentally ill." The Centre for Addiction and Mental Health also offers numerous approaches to anti-stigma and there are a myriad of local anti-stigma activities throughout the country. And the Canadian Alliance on Mental Illness and Mental Health (CAMIMH) hosts a yearly Champions of Mental Health Award Luncheon (October 4th, 2006).

The United States, through the National Alliance on Mental Illness (NAMI) has mounted some longer term campaigns (StigmaBusters, for example), and has some multi-year programs (In Our Own Voice). The Substance Abuse and Mental Health Service Administration (SAMHSA) also sponsors anti-stigma campaigns and has established a resource centre called Address Stigma and Discrimination (the ADS Centre). It hosts the Elimination of Barriers campaign that is piloting local projects in several states. The United Kingdom has the most efforts underway, while Australia has only a few.

Best practices from New Zealand

An example of a best practice initiative is a national and highly successful anti-stigma campaign in New Zealand,[75] called Like Minds Like Mine. It has been evaluated on multiple levels and has shown the capacity to shift both attitudes and behaviours. The components that have made this campaign effectives are as follows:[76]

- Dedicated senior government leadership willing to champion the project.
- Adequate and sustained funding over the long haul
- Taking the long view – continue activity over time.
- Well-defined goals - awareness is not enough. Attitudinal and behaviour changes must result.
- Clear understanding of the intended audience
- Approaching the problem from multiple and integrated directions - education, policy and procedural changes, new practices and improved standards.
- Using the wisdom and experience of the people who have "been there," to develop and deliver the change messages for the intended audience.
- Evaluating right from the outset. And using evaluation results to correct change messages and change activities on a continuing basis, as well as to measure outcomes.
- Communicating results broadly – What has been learned, what should change and what is effective?

Moving forward on a consumer- and family-driven research agenda

This review points to a number of areas for future Canadian research that have particular resonance for consumers and families:

[75] New Zealand is a small country and may have had an easier time launching a coordinated national campaign. Nonetheless, it provides valuable lessons on what works.
[76] For full information, See: www.likeminds.govt.nz

5. Self-stigma is the enemy within. It renders a person complicit with the injustice of externally imposed discrimination and stereotyping. Yet the processes by which people come to believe that they deserve ill-treatment and ostracism are ill defined. As result, mechanisms to counteract self-stigma are less well articulated. There is a rich source of ideas in the recovery movement that require further thought and, perhaps, re-framing in terms of the mechanisms that address the effects of self-stigma. Recovery, along with self-empowerment, may be among the premiere antidotes to self-stigma because they change one's own ideas about self and the world. **Self-stigma is an important area for further research.**

6. Anti-stigma campaigns are aimed at changing others' attitudes and beliefs. The sheer amount of activity offers many useful examples about what works, and what does not. In Canada, there is no need to re-invent the wheel. The time has come for action. Consumers and families are less concerned with measuring the extent and impact of stigma (they already know that). **Research attached to action would be highly valued.**

7. **Consumers and families must be involved**, not only in defining the actions to be taken and delivering the resulting campaigns, but also in the complete research process. They must participate in developing the research questions, collecting data and in analyzing results. No one cares more than they do about outcomes. As a result, they are the funders' best allies because they, too, want to ensure that investment pays off.

8. Often research, like many of the anti-stigma campaigns, can be piecemeal and unconnected. People don't hear about results and thus, are unable to make use of what has been learned. **Consumers and families have active organizations that can be utilized for the dissemination** of both the campaigns and the research findings.

Conclusions

The impact of stigma is multi-level, individually and socially. The damaging messages are internalized, leading to a sense that there is nothing to be done to overcome mental illness. Friends, family and co-workers may reject and ostracize, increasing isolation exactly at the time when support and understanding are required. Social structures that should protect either turn a blind eye or actually participate in discriminatory acts, leaving people feeling abused and abandoned. Investment in research, treatment and support is scant so that when people find the courage to reach out for help, they find limited resources, waiting lists and health care providers who may, themselves, hold stigmatizing attitudes.

Consumers and families recognize all too clearly that stigma can kill. They have a sense of urgency driven by personal experience that can be used to fuel change. However, as this review demonstrates, changing attitudes and behaviours is extraordinarily difficult. While there is a lot of activity focused on anti-stigma campaigns and, while there is some evidence that beliefs are shifting,[77] there is much work left to do.

[77] Thompson, A. Stuart, H. Arboleda-Florez, J. Warner, R. Dickson, R. (2002). Attitudes about schizophrenia from a pilot site of the WPA world-wide campaign against stigma. Social Psychiatry and Psychiatric Epidemiology. 37, p. 475 – 482.

Appendix 1

Measurement tools

There are a variety of tools available that have been utilized to measure stigma associated with mental illness on multiple levels.

Experiences of stigma: A 21-item survey instrument developed by Otto Wahl in collaboration with consumers who helped identify indicators of stigma through their personal experience.[78]

Stigma coping strategies: A questionnaire utilizing the Likert scale for assessing levels of stigma by Bruce Link and colleagues. The scale has four headings: deviation and discrimination, coping strategies that indicate secrecy, avoidance-withdrawal and the need to educate others.[79]

Perceived devaluation: Link and colleagues have also produced a 20-item scale for studying people's perceptions of stigma.[80]

Internalized stigma: This scale measures how much people have adopted a stigmatized identity.[81]

Attributions: The Chicago Consortium for Stigma Research has made available a number of questionnaires that measure attitudes and behaviours in relation to a vignette describing a person with mental illness.[82]

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[78] Wahl, O. (1999). Mental health consumers' experience of stigma. Schizophrenia Bulletin. Vol 25 (3), p. 467 – 478. Abstract available at: http://www.ncbi.nlm.nih.gov/entrez/query.fcgi?cmd=Retrieve&db=PubMed&list_uids=10478782&dopt=Abstract

[79] Link, B. Mirotznik, J & Cullen, F. (1991). The effectiveness of stigma coping orientations: Can negative consequences of mental illness labelling be avoided. Journal of Health and Social Behavior. 32(3), p. 302 – 320. Abstract available at: http://www.ncbi.nlm.nih.gov/entrez/query.fcgi?cmd=retrieve&db=pubmed&list_uids=1940212&dopt=Abstract

[80] Sirey, JA. et al (2001). Perceived stigma and patient-related severity of illness as predictors of anti-depressant adherence. Psychiatric Services. 52, p. 1615 – 1620. Available at: http://ps.psychiatryonline.org/cgi/content/abstract/52/12/1615

[81] Ritscher, J & Phelan, J. (2004). Internalized stigma predicts erosion of morale among psychiatric outpatients. Psychiatry Research. 129(3), p. 257 – 265. Available at: http://www.stopstigma.samhsa.gov/topics_materials/g-books.htm

[82] Available at: www.stigmaresearch.org/index.cfm

Appendix 2

Conferences, organizations, journals, reports and books

Conferences

1. Stigma and Global Health: Developing a Research Agenda. Held in Bethesda Maryland in September 2001. Sponsored by the Fogarty International Centre. http://www.stigmaconference.nih.gov/ Results:

> Bethesda, Maryland — The Fogarty International Center (FIC) of the National Institutes of Health (NIH) *announced a new research program to support international collaborations to study stigma and global health (in the wake of the conference).* FIC, with 11 NIH partners, the Health Research Services Administration, and the Canadian Institutes of Health Research (CIHR) lead by the Institute of Neurosciences, Mental Health and Addiction (INMHA) with the International Development Research Centre, has issued a Request for Applications for the Stigma and Global Health Research Program. The current combined financial commitment of the Stigma and Global Health Research Program partners is approximately $2.75 million for the first year. Total support will be approximately $11 million over the next five years.

2. Report of the Research Workshop on Health-related Stigma and Discrimination. http://www.kit.nl/frameset.asp?/development/html/products___services.asp&frnr=1&ItemID=2538 Conference held in *December 2004* in Soesterber, The Netherlands, sponsored by the Royal Tropical Institute (KIT).

3. Mental Health in the Workplace: Delivering Evidence for Action, April 28 – 29, 2004 and, Workplace Mental Health Conference June 2 – 3 2005 Montreal

Both sponsored by CIHR

CIHR (with INMHA as lead) will spend the next 10 years studying mental health in the workplace. One of the goals of the $3.2 million initiative is to reduce the *stigma* of mental illness, so that workers are less reluctant to seek help for their problems. Other research may focus on better understanding the differences between those who thrive under pressure and those who struggle. By creating a solid base of research evidence, the initiative will provide a foundation for action to lessen the toll of mental illness in the workplace. The initiative will also train new researchers in the area and build a coalition to identify research priorities and develop innovative policy and program intervention and identify best practices.

4. Shifting attitudes and behaviour to mental health. The first international SHIFT conference on stigma and discrimination held in March 2006 in Manchester, England. By invitation only.

Special Journal Editions focused on stigma

Perlick, D. (2001) Special section on stigma as a barrier to recovery Psychiatric Services 52(12). Available at: http://ps.psychiatryonline.org/cgi/content/full/52/12/1613

Visions: Stigma and discrimination (Fall 2005). Vol 2 (6). A publication of the BC Canadian Mental Health Association. Available at: http://www.cmha.bc.ca/resources/visions/stigma

Stigma and Global Health: Developing a Research Agenda
The Lancet, Volume 367, Number 9509, 11 February 2006 Available at:
http://www.thelancet.com/journals (registration is free)

The Health Repercussions of Stigma (2004). The Pfizer Journal. Available at:
http://www.thepfizerjournal.com/default.asp?a=journal&n=tpj37

Pending: A special edition of Psychology, Health and Medicine on stigma (due in 2006).

Books

Corrigan, P (ED) (2005). On the stigma of mental illness: Practical strategies for research and social change. Washington: American Psychological Association.

Corrigan, P. (2001). Don't call me nuts: Coping with stigma and mental illness. Tinley Park, Ill: Recovery Press.

Sayce, L. (2002). Psychiatric patient to citizen: Overcoming discrimination and social exclusion. Basingstoke, England: MacMillan.

Wahl, O. (1995). Media madness: Public images of mental illness., New Brunswick, NJ: Rutgers University Press.

Wahl, O. (1999). Telling is risky business: Mental health consumers confront stigma. New Brunswick, NJ: Rutgers University Press.

General texts:

Falk, G. (2001). Stigma: How we treat outsiders. Amherst, New York: Prometheus Books

Mason, T. Carlisle, C. Watkins, C. % Whitehead, E. (2001). Stigma and social exclusions in health care. London, England: Routledge

Groups focused on the issue of stigma

Chicago Consortium for Stigma Research www.stigmaresearch.org
Patrick Corrigan, Director Centre for Psychiatric Rehabilitation, Evanston IL

International Consortium for Research and Action against Health-related Stigma
Graham Scrambler, Professor of Medical Sociology, University College London, UK. Available at:
http://www.kit.nl/frameset.asp?/development/html/products___services.asp&frnr=1&ItemID=2538

Projects and reports

Mind Over Matter: Improving media reporting of mental health (2006)
http://www.shift.org.uk/mindovermatter.html published in the wake of an outcry in Britain when a newspaper headline reported "Bonkers Bruno Locked Up" – referring to the mental health problems of former heavyweight champion Frank Bruno.

Reducing stigma and discrimination: What works? (June, 2003) Showcasing examples of best practice of anti-discrimination projects in mental health. Conference report: Rethink / Institute of Psychiatry conference held in Birmingham, England. Available at:
http://www.iop.kcl.ac.uk/iopweb/departments/home/default.aspx?locator=461

From Here to Equality. Available at: http://www.shift.org.uk/Aboutus National Anti-stigma Strategy for the UK (June 2004).

Guides for media for fair reporting on mental illness

Mindframe Media and Mental Health is an Australian project that is designed to ensure proper reporting of suicides. See: http://www.mindframe-media.info/about/index.php

Mindout for Mental Health (a UK anti-stigma project) publishes a quarterly newsletter called Mindshift and has developed a guide for journalists so they can be more balanced in their published reports on mental health and mental illness. Mindshift: A guide to open-minded media coverage of mental health. Available at: http://mindout.clarity.uk.net/p/p03-media.asp

Appendix 3

Anti-stigma approaches that don't work

Messages:

Complaining: If only people understood these problems better…
Blaming: Your attitudes and actions hurt people with these problems…
Shaming: If you were a good person, you'd be kind to people with these problems…
Lecturing: Don't you know? This health condition is.. genetic, non-infectious, not their fault, a chemical imbalance…
Frightening: This health problem could strike you or someone you love at any time…
Threatening: Create services *now* or untreated people will be roaming the streets of your neighbourhoods.

Methodologies:

Messages developed without the involvement of people who have "been there." – These messages don't capture reality and miss the mark.
Time-limited approaches - often under funded and with limited reach.
One-dimensional approaches – for example, public service announcements with no other activities attached to them.
Hoping for the best – Creating a program or campaign with no thought to assessing its effectiveness.

Appendix 4

Examples of anti-stigma campaigns/activities

There are many localized campaigns in Canada and throughout the United Kingdom, Australia, New Zealand and the United States. The examples listed here are the more major campaigns, some of which are provincial and some which are national. Also reviewed are arts programs and film festivals that feature work by and about people with mental illness.

World-wide Campaigns

Open the Doors, World Psychiatric Association

Focusing on the stigma associated with schizophrenia, this is a world-wide campaign that is expressed through local action groups in 20 countries. Each group has access to a training manual but must find funds for their campaign themselves. The specifics of these local campaigns can be viewed at: http://www.openthedoors.com/english/01_05.html

World Mental Health Day (October 10th, 2006) is used as a focus for anti-stigma activity

Canada

There is help, there is hope (Center for Addiction and Mental Health - CAMH)

A public awareness campaign for depression and alcohol problems that provides information about what symptoms to look for, how to get help and that recovery is possible.

Talking About Mental illness (TAMI) (a joint project between CAMH, the Mood Disorders Association of Ontario, the Canadian Mental Health Association and other local agencies)

Started in 1988 and originally called Beyond the Cuckoo's Nest, TAMI offers a community and teacher's guide to implement the program locally. It is aimed at high school students 15 years and older and involves people who have had mental health or addiction problems presenting to students.

Courage to Come Back Awards (CAMH)

A public education and fundraising gala evening where people who've overcome serious mental health or addiction problems are honoured

Transforming Lives (CAMH)

Public services announcements where prominent Canadians (Ron Ellis for example) talk openly about their mental health or addiction problems and how they overcame them.

Imagine…. 2004 (The Canadian Psychiatric Research Foundation's national campaign)

Originally called Project Breakthrough, this campaign involves a series of public service announcement and newspaper ads that state: "Heart disease. Just another excuse for lazy people not to work" or "Wheelchair access? Can't those people learn to help themselves?" with the line, "Imagine if we treated everyone like we treat the mentally ill." Evaluation available at: www.thcu.ca.

Depression pays a call (The Canadian Mental Health Association's national campaign)

Public service announcements for television where depression is personified as a sinister man that comes to call on the unsuspecting (2004). CMHA also utilized Chantel Kreviazuk (singer from Winnipeg) as a spokesperson for a series of PSAs. Present anti-stigma and education campaigns focus on mind/body fitness with the message: "It's OK to look after your body. Just don't forget about your mind."

We all belong (2000 – 2005)

The Northeast Mental Health Public Education Campaign ($1.5 million):
Changing Community Attitudes about Mental Health and Mental Illness

A public education campaign about mental health reform in Ontario. This was a pilot project of the Northeast Mental Health Implementation Task Force, funded by the Ontario Ministry of Health and Long-Term Care and focused on northeastern Ontario.

Running from April 2000 to March 2005, the campaign was intended to help northern communities prepare for community-based mental health care and treatment by informing them of changes occurring within their regional mental health system and by changing community attitudes about mental health and mental illness.

Formal description:

- The campaign mission was to assist with the implementation of mental health reform in Northeastern Ontario through the shaping of public attitudes, so that people with mental health problems have an improved sense of acceptance, purpose, and freedom in their communities.

The We All Belong campaign was a region-wide initiative with the following partners:

- Canadian Mental Health Association - Northeastern Branches
- Canadian Mental Health Association - Ontario
- Centre for Addiction and Mental Health
- Northeast Mental Health Centre
- North East Ontario Network
- Nipissing University
- Muskoka/Parry Sound Community Mental Health Services

Mind Your Mind

www.mindyourmind.ca

This London, Ontario-based site is **aimed at youth** who are looking for information on mental health and ways of coping with stress. It offers young people resources both to get help and to give help. It provides information through art and film projects, stress busters and a newsletter called Lip Service.

It's most recent issue of Lip Service (March 2006) focuses on the tools to fight stigma. Available at: http://www.mindyourmind.ca/info/lip-service.asp The campaign has limited funding (Agape

Foundation of London) and is aimed at a **local** audience, but it is highly creative and completely in tune with youth culture and the media they use to communicate.

Champions of Mental Health Awards Luncheon (October 4th, 2006) is sponsored by the Canadian Alliance on Mental Illness and Mental Health (CAMIMH) and honours Canadians who have contributed to greater awareness and/or changes in public policy over the past year.

In addition, **Mental Health Week** (May 1 – 7th 2006 and **Mental Illness Awareness Week** (October 1 – 7th) are used a focuses for anti-stigma campaigns.

United Kingdom

Changing Minds (UK and Ireland) 1998 – 2003

http://www.rcpsych.ac.uk/campaigns/cminds/index.htm

Sponsor: Royal College of Psychiatrists

Slogan: Stop, think, understand.

Description from website:

The Changing Minds campaign is trying, in a variety of ways, to encourage everyone to stop and think about their own attitudes and behaviour in relation to mental disorders. If we do stop and think, we will almost certainly understand more, and as a result become more tolerant of people with mental health problems.

The aims of the Changing Minds campaign are:

To increase public and professional understanding of different mental health problems, including:

- anxiety
- depression
- schizophrenia
- Alzheimer's disease and dementia
- alcohol and other drug misuse
- anorexia and bulimia

To reduce the stigma and discrimination against people suffering from these problems.

The areas the Campaign has been looking at are the public's perceptions of:

- dangerousness
- self-harm
- the outlook for people suffering with mental illness
- communication problems

The campaign involved educational leaflets, booklets and videos aimed at a variety of audiences.

Every Family in the Land

A comprehensive publication of the Royal Society of Medicine's Psychiatry Lecture Section. It is "proudly medical" in its core approach. It was the result of activities related to the Changing Minds Campaign. It is also available at www.stigma.org

A baseline survey of 1700 people was taken in 1998 before the start of the campaign. Crisp, A. Gelder, M. Rix, S. Meltzer, H. & Rowlands, O. (2000). Stigmatization of people with mental illness. British Journal of Psychiatry. Vol 177, p. 4 – 7. Available at: http://bjp.rcpsych.org/cgi/content/full/177/1/4

"Results: Respondents commonly perceived people with schizophrenia, alcoholism and drug addiction as unpredictable and dangerous. The two latter conditions were also viewed as self-inflicted. People with any of the seven disorders were perceived as hard to talk with. Opinions about effects of treatment and prognosis suggested reasonable knowledge. About half the respondents reported knowing someone with a mental illness. "

Stigma.org

A website developed from the Defeat Depression campaign (a precursor of the above Changing Minds Campaign).

From website:

Stigma.org offers world-wide subscriptions to organizations, educational bodies, government institutions or any individuals who agree to collaborate according to the following principle

- That members shall contribute in whatever way they can to work to prevent discrimination and stigmatization against those people with physical and mental health problems.

The momentum and power of this campaign is based on its united strength of purpose and the inclusion of people it represents.

The site seems a repository for some of the materials from both the Defeating Depression and the Changing Minds Campaigns.

MIND

This is the mental health charity of England and Wales. It publishes Openmind, a bi-weekly newsletter. It also invites people to join ion its campaigns – often ad hoc in design, to respond to emerging issues. People become Members of Campaign Group and receive news on how they can get involved nationally or locally. It publishes and Campaign Skills booklet that helps people and groups mount their own campaigns on an issue of particular interest to them – i.e. campaigning and the law, how to work with MPs, how to evaluate your campaign etc.

Available at: http://www.mind.org.uk/News+policy+and+campaigns/Campaigns/CAG.htm

MIND sponsored a "Respect" campaign focused on the workplace in the 1990's but it has long since ended.

SHIFT

Shift is a five year initiative (2004-2009) in England to tackle stigma and discrimination surrounding mental health issues. The aims of the campaign are set out in a plan called "From Here to Equality". The goal is to create a society where people who have mental illness are treated equally. Shift builds on the *Mind out for Mental Health* campaign, which ran from 2001 to April 2004. Shift is part of the National Institute for Mental Health in England (NIMHE), a Government organization that is responsible for supporting positive change in mental health and mental health services.

Campaign components:

Media watch and advocacy. For example, Mind Over Matter: Improving media reporting of mental health. Available at: http://www.shift.org.uk/mindovermatter.html

There There Magazine. Available at: http://www.shift.org.uk/therethere

A campaign that looks at mental health in relation to sport – especially football.

Conferences: *Shifting attitudes and behaviour to mental health*. The first international SHIFT conference on stigma and discrimination held in *March 2006* in Manchester, England. By invitation only.

Helplines and support

Mental health and youth

Rethink (UK)

Rethink is the largest severe mental illness charity in the UK. As of 2nd July 2002 'Rethink' became the new operating name for the 'National Schizophrenia Fellowship'.

Dedicated to improving the lives of everyone affected by severe mental illness, whether they have a condition themselves, care for others who do, or are professionals or volunteers working in the mental health field.

With more than 30 years of experience, and over 1400 staff, Rethink provides a wide range of community services including employment projects, supported housing, day services, help lines, residential care, and respite centres..

Rethink's work is overseen by the Board of Trustees, of whom the majority are carers and users. Rethink Northern Ireland Office has their own local committee structure, and is responsible for their own management and governance.

Most of Rethink's funds come from statutory funders such as health authorities, but these are bolstered by sources including central government departments, the European Social Fund, trusts, companies and individuals. Rethink's income is currently over £41 million per year.

In all its work, Rethink is committed to promoting equality, choice, dignity, respect and access to care and support. More information available at: http://www.rethink.org

Mindout for Mental Health

Sponsored by the UK Department of Health, Mind out for Mental Health is an awareness and action campaign, working to bring about positive shifts in attitudes and behaviour surrounding mental health. In active partnership with organizations from a wide range of sectors, Mind out for Mental Health produces a range of communications materials and runs a series of workshops and events. See www.mindout.clarity.uk.net

It produces pamphlets and resource document on mental health in the workplace, mental health and youth, and a guide for managers to deal with a worker who has a mental illness and a local campaign toolkit, among many other resources. It also has a media watch.

It publishes a quarterly newsletter called Mindshift and has developed a guide for journalists so they can be more balanced in their published reports on mental health and mental illness. Mindshift: A guide to open-minded media coverage of mental health. Available at: http://mindout.clarity.uk.net/p/p03-media.asp

See me (Scotland)

Begun in 2003, it is an anti-stigma campaign to stop the "stigma of mental ill health." It includes a media watch, and a section devoted to mental health in the workplace. On its site, See Me quotes the Scottish Press Complaints Commission's code of practice:

"The press should avoid prejudicial or pejorative reference to a person's race, colour, religion, sex or sexual orientation or to any physical or mental illness or disability."

Available at: http://www.seemescotland.org.uk/links/index.php

Australia

Note: In April 2006**,** The Australian government announced an investment of $1.8 billion in new funds for mental health in that country. New programs will be created to increase community awareness of mental illness particularly in relation to the connection between drug abuse and subsequent mental health problems. Announcement available at: http://www.aushealthcare.com.au/documents/news/6994/Howard%20050406.pdf

beyondblue

Established in 2000, beyondblue is a national non-profit organizations focused on awareness and advocacy regarding depression and anxiety. Its programs involve community awareness and destigmatization campaigns such as television advertisements and community presentations, advocacy on behalf of and with people with mental illness and their families, prevention and early detection programs, training to improve understanding of depression and anxiety among primary care providers and increased investment in research and translation of findings into action. The organization is funded on a five-year basis and is approved through 2010. Measurement of its success involved monitoring media exposure and coverage of issues important to beyondblue. Anecdotally, there have been other surveys that have shown improved knowledge about depression and anxiety among the general population.

Available at: www.beyondblue.org.au

Mindframe Australia

The Mindframe-media website, based on the print resource "Reporting Suicide and Mental Illness," provides practical advice and information to support the work of media professionals by informing them about sensitive and appropriate reporting of suicide and mental illness. It also includes a media monitoring component. It is overseen by the National Media and Mental Health Group which was established in 2000 to provide advice about appropriate initiatives and methods to encourage the Australian media to report and portray suicide and mental illnesses in a way that is least likely to cause harm, induce copycat behaviour, or contribute to the stigma experienced by people who have a mental illness.

Available at: http://www.mindframe-media.info/about/index.php

SANE Australia

SANE Australia is an independent national charity working for a better life for people affected by mental illness through campaigning, education and research.

It is not-for-profit and depends on donations or grants.

SANE runs award winning anti-stigma campaigns, has a helpline and a media watch centre to point out stereotyping in reporting on mental illness. It also produces advocacy reports that monitor government investment in mental health services, for example, Dare to Care (2004), a report highly critical of the Australian mental health strategy.

See: http://www.sane.org/index.php?option=displaypage&Itemid=259&op=page

New Zealand

Like Minds Like Mine

Long term funding from the Ministry of Health

See: www.likeminds.govt.nz

The campaign developed its messages by working with consumers and family members and listening to their views. It has now been running for five years.

Components:

Ad campaigns for televisions and radio featuring prominent New Zealand citizens from all walks of life (called Famous People) talking about their experience of mental illness.

Human Rights initiative called Korowai Whaimana (the empowerment cloak) created to restore mana - balance). It involves a one-day workshop delivered by people with mental illness to people with mental illness to help them understand and exercise their rights under New Zealand's human rights legislation.

Policy project: It identifies federal, state and municipal polices and practices that may affect people with mental illness (employment, housing, insurance, services for families etc.) and seeks to alter them in ways that make real change.

Rosalynn Carter Fellowships for Mental Health Journalism: New Zealand has obtained two fellowships for their country's needs and they are awarded annually. The United

States awards 6 and South Africa two annually. The fellowships are $10,000 and awarded to journalists who want to study and report on a mental health issue in such a way as it reduces stigma.

Discrimination survey: A survey of 785 people with mental illness was conducted and the results were used to support the needed changes under the policy and practices project.

Regional and local contracts: Organizations and groups are invited to apply for funds to develop local programs that include education and training, creating a speakers bureau and sponsoring community events, all aimed at reducing stigma.

Articles and reports: All activities of the campaign are written up for publication in the media or in professional journals.

Evaluation: The project has been the subject of extensive evaluation from pre-testing to produce the most effective messages for the ad campaign, to evaluation of the effective of the ad campaign (308 people are surveyed after each run of the campaign and they report reduced experiences of stigma), and four national surveys of the general population that demonstrate a marked change in public attitudes towards people with mental illness after each ad campaign.

Awards: Silver Medal for Sustained Success in Advertising – Auckland, October 2005 – the criteria was that a campaign had to show success over three years or more. The campaign has been running for five years and this is its fourth award.

Shows measurable results: "Research as part of the Like Minds, Like Mine project shows that acceptance of people with mental illness increased between 1997 and 2004. Respondents' acceptance of someone with mental illness working for them increased from 61 percent to 75 percent. Respondents' willingness to accept someone with mental illness as a workmate increased from 69 percent to 80 percent.

United States

The State of Depression in America (2006)

This is a report on the incidence levels of depression accompanied by a video narrated by Mike Wallace and others, including prominent spokespeople, researchers and people who've experienced mental illness. It was developed by the Depression and Bipolar Support Alliance and can be viewed at:
http://www.dbsalliance.org/stateofdepression1.html

Elimination of Barriers Initiative (EBI) – sponsored by the ADS centre

President Bush's New Freedom Initiative calls for community and societal integration of persons with mental illnesses. With this in mind, CMHS (SAMHSA's Centre for Mental Health Services) developed the EBI to work with States and other stakeholders to reduce the stigma and discrimination associated with mental illness. Over a three-year period, the EBI will test campaign models and public education materials in eight pilot States: California, Florida, Massachusetts, North Carolina, Ohio, Pennsylvania, Texas, and Wisconsin. Pending a full evaluation, CMHS will distribute evidenced-based public education practices to States and communities nationwide. Some results regarding its effectiveness were recently published: Corrigan, P. & Gelb, B. (2006). Three programs that use mass approaches to challenge the stigma of mental illness. Psychiatric Services. Vol 57, p. 393 – 398.

See full description of the campaign at:
http://www.stopstigma.samhsa.gov/ebi.htm#whatisebi

ADS Centre

SAMHSA's Resource Center to Address Discrimination and Stigma (ADS Center) provides practical assistance in designing and implementing anti-stigma and anti-discrimination initiatives by gathering and maintaining best practice information, policies, research, practices, and programs to counter stigma and discrimination; and actively disseminating anti-stigma/anti-discrimination information and practices to individuals, States and local communities, and public and private organizations.

1 800 540 0302

ADS Centre
11420 Rockville Pike
Rockville, MD 20852
Email: stopstigma@samhsa.hhs.gov

Available at: http://www.stopstigma.samhsa.gov/index.html

Voice Awards

The SAMHSA/CMHS Voice Awards were developed to acknowledge film, television, and radio writers and producers whose work has given a voice to people with mental health problems by portraying them in a dignified, respectful, and accurate manner. The Voice Awards also acknowledge the efforts of mental health advocates, departments of mental health, and other partners in eight States piloting the Elimination of Barriers Initiative (EBI). For more information about the Eliminations of Barriers Initiative and the 2005 SAMHSA/CMHS Voice Awards, see http://www.allmentalhealth.samhsa.gov.

Taking Action Tour

Staring March 1, 2006, it includes 49-city tour of multiple rock and country bands to publicized suicide prevention and the Paul Wellstone Bill to be re-introduced to congress arguing for the same benefits for people with mental illness as those who have a physical illness.

Paul Wellstone Equitable Treatment Act:

An act seeking to replace the 1996 parity act in the US (which is thought inadequate and which does not cover substance abuse. It has not yet been passed but there is a movement to have it re-introduced in Congress (last attempt – April 2003). Senator Paul Wellstone was from Minnesota and was killed, along with his family, in a plane crash in 2003. More information available at:
http://www.counseling.org/Content/NavigationMenu/PUBLICPOLICY/WASHINGTONUPDATEARCHIVESCTONLINE/WellstoneMentalHealt.htm

StigmaBusters

NAMI StigmaBusters is a group of dedicated advocates across the country and around the world who seek to fight the inaccurate, hurtful representations of mental illness. Whether these images are found in TV, film, print, or other media, StigmaBusters speak out and challenge stereotypes in an effort to educate society about the reality of mental

illness and the courageous struggles faced by consumers and families every day. StigmaBusters' goal is to break down the barriers of ignorance, prejudice, or unfair discrimination by promoting education, understanding, and respect.

NAMI publishes “stigma alerts” and people who have joined up as a “stigmabuster” write, campaign, just generally make themselves heard regarding their displeasure (or congratulations) regarding media portrayals of people with mental illness. For example, they vilified Me, Myself and Irene (Jim Carrey) and endorsed a Beautiful Mind (Russell Crowe). A lot of their work is lower profile than these two prominent examples, however, StigmaBusters, rightly or wrongly, is credited with the cancellation of This is Wonderland, a CBC series that portrayed the mental health court at Old City Hall in Toronto (see Mental Health Notes March 30th, 2006. Available at: www.ontario.cmha.ca).

In Our Own Voice

NAMI also sponsors In Our Own Voice: Living with Mental Illness, a program that offers video and presentation materials which can be used by trained consumers and families to present on mental illness in their communities. NAMI offers training sessions for consumer and family presenters.

The arts

Mad about the Arts, Ottawa

Mad About the Arts is a coalition of Ottawa-based mental health agencies, consumers, arts organizations and interested community members. It organizes or sponsors art and cultural events with the aim of increasing public awareness about mental health issues and promoting sensitivity, acceptance and support for those who experience mental health problems.

Stigma Busters Productions is a non-profit enterprise dedicated to promoting mental health and reducing the stigma of mental illness through the arts. It was launched by Linda O'Neil, a long-time mental health activist and volunteer, in 2004.

Contact: Francine Page
613 737 7791 x124
fpage@cmhaottawa.ca

Mindscapes

This juried art exhibit celebrates the talent of visual artists who live with a mental illness or an addiction. It was held in 2003 and 2004 at the National Art Gallery in Ottawa and was co-sponsored by the Canadian Mental health Association, the Institute of Neurosciences, Mental health and Addiction and Les Impatients. There are plans to re-mount the show in Quebec City in the fall of 1006. See http://www.cmha.ca/bins/content_page.asp?cid=6-647

Workman Theatre (CAMH)

Plays, poetry, visual art, music and performance art staged at the Queen Street site of CAMH. Also the host of the annual Rendezvous with Madness film festival.

Shadows of the Mind

A film festival held in Sault St Marie

Visions and Light

A film festival held in Thunder Bay.

The White Noise

Part of the German Open the Doors anti-stigma campaign. It is a film about a young man with schizophrenia which won the Max-Ophuls Prize in 2001 and the German Film Prize for best actor.

Brochures

Stop Exclusion, Dare to Care: Brochure published in honour of World Mental Health Day 2001. Available at: www.emro.who.int/mnh/whd/WHD-Brochure.pdf

Challenging stereotypes: An action guide. A how-to manual for consumers who want to engage with media. Available at: http://www.mentalhealth.samhsa.gov/publications/allpubs/SMA01-3513/sma01-3513-04.asp