Addressing Stigma: Increasing Public Understanding of Mental Illness

Presented to:

THE STANDING SENATE
COMMITTEE ON SOCIAL AFFAIRS,
SCIENCE AND TECHNOLOGY

May 28, 2003

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Introduction

"Powerful and pervasive, stigma prevents people from acknowledging their own mental health problems, much less disclosing them to others." US Surgeon General, 1999 [1]

What is stigma?

- An inescapable consequence of the human tendency to order the world by demarcating selfhood and otherness
- Our fragile sense of self-identity is reinforced through the pathologization of pariahs
- To set the sick apart sustains the fantasy we are whole.[2]

Stigma is a serious impediment to the well-being of those who experience it. It affects people while they are ill, while they are in treatment, and healing, and even when a mental illness is a distant memory. Clearly, it seems difficult to get rid of the stigmatizing labels once the stigmatizing behavior has occurred.[3] Goffman noted that it was the ancient Greeks who originated the term "to refer to bodily signs designed to expose something unusual and bad about the moral status of the signifier" [4]

On a systemic level, stigma as a social phenomenon has a strong influence on the policies that govern the nature of, access to and funding for treatment and support, eligibility for social assistance or the right to refuse treatment. At the level of the community, stigma may affect how organizations including social service agencies, employers, health care providers, or schools respond to individuals with a mental illness and to their families. At the individual level, stigma prohibits people from seeking the treatment they need, creates profound changes in identity and changes they way in which they are perceived by others. There is no doubt that reducing stigma is a daunting and complex process.

It is important to underline that the challenge is as much about compelling people to change their attitudes towards and/or be more understanding of those who struggle with a mental illness as it is **to move them to recognize and acknowledge their own mental health problems, and those of their families, friends and employees**. It is no wonder that negative attitudes towards mental illness sustain: estimates are that two-thirds of people who require treatment for a mental illness don't seek help, either because of a lack of understanding of the symptoms or because of the stigma associated with the illness and its treatments. If, as the Surgeon General commented in 1999, people don't acknowledge their own mental health problems, how can we expect them to be accepting and supportive of others.

Among the strategies found to be most effective in creating greater understanding and acceptance, are a comprehensive health promotion framework combined with a social marketing approach[5]. Various groups of people who have suffered from the effects of social stigma have managed to end or minimize that stigma by creating widespread change in social attitudes[6]. Examples have included the gay and lesbian community, and groups representing those with disabilities, AIDS or cancer. Their success has often been as a result of a broad health promotion approach.

Similarly, in the area of mental illness, what is needed is a health promotion approach, including:

- a social marketing strategy designed to raise awareness, encourage help seeking and promote positive attitudes;
- development of healthy public policy which would ensure supportive policies for social assistance, employment, housing, and health care;
- sensitization training for those who regularly come into contact with people with personal experience; and
- research to explore more effective treatments.

This paper outlines the issues that characterize the stigmatization of people who have had a mental illness, suggests evidence-based strategies for change, and offers considerations for policy makers, consumers, funders, community leaders, helping professions and employers.

On How Stigma is Manifested

This section outlines the experience of stigma by people who have experienced mental illness and their families; how it affects their lives; and identifies those barriers which result from stigmatization. Stigma is manifested by bias, distrust, stereotyping, fear, embarrassment, anger, and/or avoidance. Stigma leads others to avoid living, socializing or working with, renting to, or employing people with mental disorders, especially severe disorders such as schizophrenia [7]

Some of the ways in which stigma is manifested include:

- Avoidance of seeking treatment
- Decreased employment
- Low self worth
- Stigma by association

Impact on Help-Seeking:

Nearly two-thirds of all people with diagnosable mental disorders do not seek treatment [8]. Stigma surrounding the receipt of mental health treatment is among the many barriers that discourage people from seeking treatment [9] The stigmatization of mental illness and the lack of information on the symptoms of mental illness are seen as the main barriers to seeking help for mental health problems. [10]

Impact on Employment:

Stigmatization is generally associated with decreased employment. Consumer Experience with Stigma: Results of National Survey was the first to focus on the experience of individuals with severe mental illness and details pervasive discrimination in the workplace that prevents them from reaching their full professional and personal potential. Seven out of ten said they have been treated as less competent by others when their illness is revealed. Three out of four said they avoid disclosing their illness to anyone outside their immediate families. Three quarters also stated that they have learned not to reveal their psychiatric histories on job applications [11] Although this survey focused on the experience of those with severe mental illness, we now know similar fears exist about disclosure to employers for those who experience more mild forms of mental health problems as well.

Impact on Self-Worth:

Stigma leads to low self-esteem, isolation, and hopelessness. [12] [1] , Further, low self-worth in response to stigmatization is found to be a predictor of poorer social adjustment. [13]

Impact on Families:

Stigma affects not only people with mental illnesses, but their families as well. Families commonly report 'stigma by association' resulting in discriminatory and prejudicial behaviors towards them[14].

On Factors which contribute to stigmatization:

Consistent with a comprehensive health promotion framework which acknowledges that barriers to health can be wide-ranging, a review of the literature finds that there is a broad range of factors which contribute to the way in which people with mental illness are viewed. Some of the common factors include:

- Label of mental illness
- Appearance
- Illness related behavior
- Characteristics of treatment
- Socio-economic status
- Media depiction

Findings indicate that labels, even in the absence of aberrant behavior, can contribute to stigma[15] Further, individuals with mental illness may be stigmatized because of illness related behavior (i.e. anxiety, tension) and social skill deficits (poor eye contact, difficulty staying on topic)[16] [17] People with physical symptoms tend to be less stigmatized that those with behavioral symptoms; people with more visible symptoms are more stigmatized than those with less readily apparent symptoms; people with symptoms considered to be "bizarre" are more frequently stigmatized than others.[18]

The characteristics of treatment also affect attitudes. Hospitalization is more stigmatizing than outpatient care; physical treatments, such as ECT, are found to be more stigmatizing than verbal treatments such as psychotherapy; individual treatment is taken to be an indicator of more serious illness than group care; people are apt to regard a person who sees a psychiatrist as more ill than one who sees a psychologist or social worker.[18]

The personal status of individuals influences the attitudes of others towards them; individuals are less likely to be stigmatized by people of similar socio-demographic backgrounds. In fact, the lower the social and economic status of the person, the more likely he or she is to be stigmatized by others. [18]

Media depiction of individuals with mental illness is commonly referred to as a challenging source of stigmatization. A recent study which examined how mental illness was portrayed in all print media on a national basis found that negative depictions predominated, with dangerousness to others and criminality being the most common at 61.3 percent and 47.3percent respectively. Positive depictions, including human rights themes, leadership and educational accomplishments occurred in only 27percent of all items[19].

On Public Perceptions of People with Mental Illness

It's important to understand the nature and scope of the problem. Surveys which examine public attitudes and beliefs of individuals with mental illness show that people commonly:

- Hold negative and exaggerated views regarding predictability and dangerousness
- Have negative views of decision making ability
- Lack understanding of the conditions and their causes.

A 1998 British survey of public attitudes about mental illness and substance abuse found that schizophrenia, alcoholism and drug addiction elicited the most negative views; however, there were widespread views that people with any of these disorders are hard to talk to, unpredictable, and feel differently than others. 50 percent of respondents acknowledged knowing personally someone with a mental illness and such personal knowledge did not affect responses on questions of dangerousness, difficulty talking to the person, or believing the person needed to pull himself together. [20]

The public appears to hold an exaggerated view of the impairment faced by those with mental illness and the level of danger they present to themselves and others. For example, although almost 75percent of respondents believe that people with schizophrenia are unable to make treatment decisions, only about half of such individuals in one recent study displayed impaired decision-making[21]

A European survey shows common lack of understanding of terms like mania, schizophrenia. Depression and schizophrenia are most commonly seen as caused by social, environmental & recent stressors in Western countries[22].

On Experience of Diverse Populations

For members of ethnoracial and ethnocultural communities, the experience of mental illness and the related stigma is increased exponentially and it has been suggested that the effects of stigma may be even more detrimental for these communities than for the general population, characterized by:

- Myths in general understanding, causes and treatment alternatives
- Somatization
- Shame
- Avoidance of help seeking

In many cases there are myths and inaccurate knowledge on the causes of mental illness and treatment possibilities among ethnoracial/ethnocultural communities. Attitudes to mental illness are often linked to the need to focus the expression of the distress on physical symptoms. In some Asian communities, stigma associated with mental illness brings shame to a family and can affect the marriage potential of other relatives, so families keep the illness private and are often reluctant to seek professional help. In some communities, religious and spiritual beliefs are linked to causes of mental illness and in some cases, influence the treatment. There is a common fear that seeking assistance from mental health services will result in being "locked up for life", fear that employment will be at jeopardy, or that immigration officials will revoke their status. [23] [24] [25] [26]For many of these communities, the stigma of mental illness is layered upon racism and other forms of discrimination, leaving individuals and their families in a complex, highly vulnerable and often helpless situation.

On Perceptions of Violence and Mental Illness

There is a commonly held perception that individuals with mental illness are significantly more likely to commit violent crimes. A less acknowledged fact is that the proportion of societal violence attributable to schizophrenia is small. The myths of the relationship between violence and mental illness contribute to:

- Exaggerated fears of dangerousness.
- Reluctance to seek help
- Exclusion to housing, jobs, and social supports.

While it is true that some people who have a mental illness do commit crimes, public perceptions of mentally ill persons as criminally dangerous are exaggerated. In fact, 80 to 90percent of people with mental illness never commit violent acts. They are actually more likely to have acts of violence committed against them, particularly homeless individuals who may also have a mental illness. As a predictor of violence, mental illness ranks well after these factors: youth, male gender, and history of violence or substance abuse. The rates of violent behaviour are slightly higher in persons with a major mental illness, such as schizophrenia, than in the general population, but the increase is quite small and is far less than that is in people who have problems with substance abuse or persons with personality disorders. According to the American Psychiatric Association, recent studies have shown that a person with psychosis or neurological impairment living in a stressful, unpredictable environment with little family or community support may be at increased risk for violent behaviour. This strongly supports the importance of society providing adequate stable housing, income and other supports for people with mental illness.

The dangerousness stereotype has endured and increased between 1950 and 1996, even though there have been large scale public education efforts focused on the nature, causes, and treatment of mental illnesses. If the dangerousness stereotype is to be addressed, we need to confront it directly. We need to understand much more about its origins, we need to learn more about how to communicate the nature of any real association between mental illness and violence, and we need to identify interventions that can bring the perceived risk in line with any real risk that may exist.[27] If the symptoms of mental illness continue to be linked to fears of violence, people with mental illness will be negatively affected through rejection, through a reluctance to seek professional help for fear of stigmatization, and through fear-based exclusion [27]

On Effective Practices

As noted earlier, among the strategies found to be most effective in creating greater understanding and acceptance, are a comprehensive health promotion framework combined with a social marketing approach[5]. It is important to look to the success of other groups including the gay and lesbian community or those representing individuals with AIDS or cancer, whose success was largely a result of a broad health promotion approach.

Similarly, in the area of mental illness, what is needed is a comprehensive health promotion framework, including:

- a social marketing strategy which includes opportunities for increasing contact with individuals who have or have had a mental illness, designed to raise awareness, encourage help seeking and promote positive attitudes
- development of healthy public policy which would ensure supportive policies for welfare, employment, housing, and health care;
- sensitization training for those who regularly come into contact with people with personal experience;
- research to explore more effective treatments.

The most promising strategy to impact negative perceptions is increasing contact with persons with mental illness. In particular, self reported previous contact with persons with mental illness is associated with more favourable attitudes[28] [29]and lower ratings of perceived dangerousness towards persons with a serious mental illness. [30] [31]Positive effects of contact could come from increased knowledge base which has been associated with reducing stigma [32] [33] [34] Other factors may mediate the relationship between contact and stigma: frequent contact with persons who only moderately disconfirm the stereotype and/or are typical to the majority group; institutional support for contact; and cooperative interaction and equal status between the stigmatized individuals and members of the community [35]. The case for increasing opportunities for contact is made even stronger by one study which found that showing a video about mental illness without opportunity for discussion, particularly with someone who has personal experience, had a negative impact on attitudes while the video followed by a discussion with an individual featured in the film had a largely positive impact. The apparent immediacy and the evocative power of video presentations cannot substitute for direct contact for the purpose of promoting positive attitude change. [36] Contact with people with mental illness who fill "normal" social roles also influence attitudes favourably. One study found that the provision of information by itself had the greatest effect on the acceptance of those with mild mental illnesses only. [18]

Research that will continue to yield increasingly effective treatments for mental disorders promises to be an effective antidote. When people understand that mental disorders are not the result of moral failings or limited will power, but are legitimate illnesses that are responsive to specific treatments, much of the negative stereotyping may dissipate.[1] Still, fresh approaches to disseminate research information and, thus, to counter stigma need to be developed and evaluated. Social science research has much to contribute to the development and evaluation of anti-stigma programs [37]

Given the influence of media on fostering public attitudes, the results of one study[38] suggest that factual information (i.e. addressing misconceptions about mental illness, including the frequency of violent behavior among persons with mental illness AND the role of media distortion on impacting community attitudes towards persons with mental illness) may be effective in nullifying the influence of negative news coverage of persons with mental illness.[35]

Another study examined three strategies for altering attributions about schizophrenia and other severe mental illnesses: education (which replaces myths about mental illness with accurate conceptions), contact (which challenges public attitudes about mental illness through direct interactions with persons who have these disorders), and protest (which seeks to suppress stigmatizing attitudes about mental illness). Results showed that education led to improved attributions. Contact produced positive changes that exceeded education

effects in attributions about targeted psychiatric disabilities: depression and psychosis. Protest yielded no significant changes in attributions about any group. [39]

Increasingly, people are obtaining information, support and treatment through the Internet and with positive outcomes. While online services are not a panacea, they nevertheless have some important advantages over other forms of care [40]Additionally, information and advice received online has been found to influence how some individuals later utilize face-to-face treatment resources. It is now possible for individuals who are concerned about stigma, to seek help for their problems without making *any* personal disclosure.[41] This raises the possibility that many who are initially reluctant to seek help, will be more likely to follow through in the future. The inherent advantages of the Internet: privacy, convenience, safety, portability and so on, ensure that help is *always* available to those with Internet access. Seeking help through the Internet does not have to involve others; in this way, stigma is neutralized.

On Reasons for Hope

"We have learned more about the brain in the last 20 years than we learned during the previous 100 years" Dr. Paul Garfinkel, President and CEO, Centre for Addiction and Mental Health

Indeed, much has been learned and, as noted in the above section, we know more about those strategies that prove effective in improving attitudes and behaviors. Throughout the world, efforts are underway to address ways in which to remove the barriers impeding people from seeking treatment for addiction and mental health problems by increasing public understanding of these conditions, their treatments and the people affected by them. Here are some results:

There is Help…There is Hope

A program of the Centre for Addiction and Mental Health which uses mass media, education in schools and workplaces, a website and community forums to increase public understanding of mental illness and addictions, with a particular emphasis on encouraging people to seek help. Results in the first two years showed that approximately 78percent of those surveyed recalled the key messages and 46percent indicated that they would seek help as a next step.

McLaughlin Addiction and Mental Health Information Centre

In response to the fragmentation of the mental health system and the difficulty with accessing information and help, CAMH will be opening a new Information Centre in the spring of 2003. The McLaughlin Addiction and Mental Health Information Centre, funded through a donation from the R. Samuel McLaughlin Foundation, will provide up to date information on mental health and addiction problems, trends, facts, statistics, programs, treatments, and prevention strategies through a toll free Information and Support Line, website, recorded messages and storefront. The Information Centre is particularly committed to reaching out to those who are currently unconnected to any forms of help and to members of diverse communities who require assistance in accessing and navigating the system.

We All Belong

The We All Belong campaign is a region-wide initiative in Northeastern Ontario with partners:

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

The We All Belong campaign is expected to increase awareness of mental health reforms in the northeast and increase sensitivity of the needs of those community members experiencing mental illness. This campaign embraces many of the best practices in changing attitudes and behaviors by creating opportunities for increased contact with people who have had experience with mental illness, and by utilizing a targeted approach by segmenting audiences such as employers, housing providers, mental health service providers, and government officials. Interest in and requests for presentations has grown significantly over the last year.

Global Business and Economic Roundtable on Addiction and Mental Health

The Roundtable consists of business, health and education leaders including the Honourable Michael Wilson, former Minister of Finance who have undersigned the proposition that mental health is a business and economic issue. This influential group has successfully attracted the attention of business leaders and governments worldwide, have brought much needed attention to the issues of mental health, and in particular, the importance of early detection, and the impact of mental health issues on work and productivity.

Courage to Come Back Awards

"The shame is in the secrecy. Shame is the illness and recovery is dignity. By sharing the secret, the power of the illness if gone". Dr. Graeme Cunningham – Recipient, 2001

Over the last ten years, almost 1000 people, including representatives of Canada's top corporations, have gathered annually to honour the extraordinary courage of individuals who are overcoming the challenges of living with addiction and/or mental illness and have chosen to use their experiences to contribute to the community. Individuals including The Honourable James K. Bartleman, Lieutenant Governor of Ontario, the Honourable Michael Wilson, The Honourable Bob Rae, former Premier of Ontario, and W. Reay MacKay, Vice Chairman, Royal Bank of Canada, make 'Courage' an annual event. Hundreds of corporations return annually to support the event, and express their commitment to doing more to increase public understanding of mental illness.

Talking About Mental Illness

This program, a partnership of the Centre for Addiction and Mental Health, the Canadian Mental Health Association, Ontario Division, and the Mood Disorders Association of Ontario, is an awareness program proven to be effective in bringing about positive change in young people's knowledge about mental illness, and in reducing stigma that surrounds mental illness. The program brings together local community partners, including youth; people with mental illnesses and their family members; clinicians; teachers; and mental health and other agency representatives to develop and organize an educational awareness program hosted by local secondary schools.

Workman Theatre Project

Since its bold launch in 1991, the Workman Theatre Project (WTP) has become known for putting a human face on mental health issues, by producing professional theatre that not only focuses on mental health but is staged by a company comprised of professional actors and people who receive mental health services. This unique arts company has attracted national and international attention. Based at the Centre for Addiction and Mental Health, WTP has performed to audiences in Canada and has connected to the rest of the world through its international festivals such as Rendezvous with Madness Film Festival and Madness and Arts 2003 World Festival. The Madness and Arts 2003 World Festival was the first international initiative which brought together actors, dancers, musicians and painters from around the world and featured art exhibits, theatre, music, dance, lectures, workshops, and panel discussions with 185 artists and academics from nine countries and succeeded in reaching over 10,000 people in its first year.

Shadows of the Mind and Vision and Lights Film Festivals

Shadows of the Mind Film Festival in Sault Ste. Marie, Ontario and Vision and Lights Film Festival in Thunder Bay are excellent examples of ways to educate and influence public understanding about mental illness through creative expression. Films and art exhibits with themes related to mental illness provide an opportunity to create a dialogue and this year, more than 3000 people combined attended the events in both communities.

Recommendations:

Consistent with the research which finds a comprehensive health promotions approach most effective in stigma reduction, consideration must be given to a comprehensive health promotion framework including the development of supportive policy frameworks, social marketing programs characterized by increasing contact with individuals with personal experience, research, and training.

1.The Need for Supportive Policy Frameworks

As noted in the previous section, contributing to the stigmatization of people with mental health problems are policies which are not supportive of recovery and which contribute to the resulting stigmatization. We need a supportive policy framework which ensures the provision of income support, housing, employment, court diversion programs and an accessible and comprehensive treatment system.

2. Social Marketing programs

Research suggests that one of the most effective ways to positively affect attitudes is to deliver relevant messages that will resonate with target audiences, encourage the public to recognize, acknowledge and disclose their own problems or those of family members, and provide information that will help the audience to access help. These kinds of initiatives create greater acceptance for conditions and their treatments. Social marketing or public education through mass media, targeted programs including workplace, schools, and service industries as well as one-on-one communication strategies will be effective in creating greater public understanding and reducing stigmatization. Further programs must be developed which reach out to diverse communities and tailored to their specific needs. Finally, there needs to be a national strategy which will coordinate efforts for maximum reach and provide appropriate levels of funding.

3. The Role of Research

Fresh approaches to disseminate research information and, thus, to counter stigma need to be developed and evaluated. Further, there is a need for research on effective approaches to stigma reduction through public education.

4. Increasing Contact:

The 'voice' of those who have been affected by mental illness must be prominent in order to impact negative perceptions. Further, creating opportunities for those who have had experience with mental illness to be involved in the development and implementation of these programs is mandatory.

5. Training

Training programs are needed to raise awareness of the experience of mental illness, sensitize to stigmatizing behaviors, and provide direction to creating more accommodating environments. Target audiences should include health and allied professionals including police, social assistance staff, employers, and educators.

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