Fighting Stigma and Discrimination Is Fighting for Mental Health

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Cet article examine les origines du stigmate et de la dicrimination et leurs répercussions majeures sur les personnes atteintes d'une maladie mentale, ainsi que sur leur entourage. Nous portons notre attention sur les efforts qui sont faits au Canada pour réduire ce stigmate, efforts dont il n'est pas fait mention dans les rapports du Comité permanent du Sénat sur les affaires sociales, la science et la technologie. L'article se termine sur dix leçons visant à la réduction du stigmate, destinées à la fois à examiner attentivement les expériences canadiennes et à fournir et à orienter les futurs débats sur les politiques à suivre. Après réflexion sur l'expérience canadienne et internationale, il apparaît particulièrement important de reconnaître que les campagnes "génériques" sont, pour la plupart, inefficaces, et que les programmes doivent être centrés sur des groupes sélectionnés.

This paper reviews the origins of stigma and discrimination and the main consequences for people with mental illness, and those around them. Stigma reduction efforts in Canada are reviewed in light of their absence from the reports of the Standing Senate Committee on Social Affairs, Science and Technology. The paper closes with ten lessons for stigma reduction intended to both distil Canadian experiences and provide guidance for further policy debate. Reflecting on the international and Canadian experiences, of particular importance is recognizing that generic campaigns are largely ineffective, and that programs must be carefully focused upon selected groups.

INTRODUCTION: STIGMA AND ITS CONSEQUENCES

Fighting stigma and discrimination is synonymous with fighting *for* mental health. According to the World Health Organization: "The single most important barrier to overcome in the community is the stigma and associated discrimination towards persons suffering from mental and behavioural disorders" (World Health Organization 2001).

Stigma is a Greek word signifying the marks that were pricked onto slaves to demonstrate ownership and to reflect their inferior social status. The ancient Greek word for prick was *stig*, and the resulting mark, a *stigma* (Falk 2001). Modern meanings of stigma are founded on Goffman's (1963) notion of *spoiled identity*, reflecting a social attitude toward mental illness that is deeply discrediting and a position of social disgrace.

Courtesy stigma or stigma-by-association (Goffman 1963) affects everything and everyone surrounding the person with a mental illness (Falk 2001; Smith 2002). For families, courtesy stigma means fear, loss, lowered family esteem, shame, secrecy, distrust, anger, inability to cope, hopelessness, and helplessness (Gullekson 1992). Families are often directly blamed for causing the illness and criticized for harbouring persons who are potentially harmful or offensive (Lefley 1992). For mental health professionals, courtesy stigma means that they themselves are seen as mentally abnormal, corrupt, or evil, and psychiatric treatments are overly scrutinized and viewed with profound suspicion, disgust, and horror. Policymakers give lowest priority to mental health issues and persistently under-fund mental health services and research compared to other, less disabling conditions (Kendell 2004; Sartorius 2004).

Self-stigma refers to the internalized feelings of guilt, shame, inferiority, and the wish for secrecy experienced by those who live with a mental illness (Goffman 1963). Because of a desire for conceal-ment, self-stigma can produce serious disruptions in family relationships and reduce normal social interactions (Link *et al.* 2001; Wahl and Harman 1989).

Discrimination refers to inequitable or unfair treatment of people with mental disorders, which amounts to denial of the rights and responsibilities that accompany full citizenship. It is a natural outgrowth of stigma. Discrimination may occur at an interpersonal level, reflecting a desire for social distance and exclusion. It may also occur at a structural level when people with mental disorders are overtly or covertly excluded from public life through a variety of legal, economic, social, and institutional means (Fink and Tasman 1992; Link and Phelan 2001).

People who live with psychiatric stigma and its consequences, often experience it as a dimension of suffering that is more devastating, life-limiting, and long-lasting than the illness itself (Schulze and Angermeyer 2003). Stigma and discrimination prevent people with mental illnesses from obtaining the simple things that others take for granted (Carne 1998). They impede social integration, interfere with the performance of social roles, diminish quality of life, and prevent timely access to treatment, effectively creating a vicious cycle of social disadvantage and disability (Stolzman 1994). In Canada, this cycle of impoverishment and disability is expressed through a clustering of social problems including unemployment, divorce, criminal activity, spousal abuse, child abuse, alcohol abuse, drug abuse, and suicide attempts. The prevalence of psychiatric illness increases with the number of social problems reported, ranging from 13 percent psychiatric disorders among those with no social problems, to over 75 percent for those with four or more social problems (Thompson and Bland 1995). Poverty, social disadvantage, weak social support, and diminished self-esteem are major obstacles to recovery. They influence long-term prognosis and promote long-term disability (Link, Mirotznik and Cullen 1991; Markowitz 1998; Prince and Prince 2002; Wahl 1999).

STIGMA AND DISCRIMINATION IN CANADA

Testimony presented to the Standing Senate Committee on Social Affairs, Science and Technology unequivocally confirms the existence of psychiatric stigma and discrimination in all walks of Canadian life. The committee members recognize the importance of treating mental and physical health with the same sense of urgency, and particularly singled out health and mental health care systems, workplaces, and schools for focused anti-stigma interventions. More specifically, they recognized the importance of implementing concerted action to reduce stigma and eliminate discrimination because of mental illness — especially the type of structural discrimination that finds expression in inequitable legal, policy, program, and research frameworks. Indeed, the committee members were particularly critical of Canada's "leadership void" in mental health that they interpreted as a clear reflection of stigma and discrimination. Consequently, they also recognized the symbolic importance that a national mental health strategy would hold for stigma reduction.

They noted that, while stigma reduction has become an important goal for many national governments, Canada does not yet have a national focus for anti-stigma activity. As part of their fact-finding mission, the committee reviewed best practices in mental health and anti-stigma programming in selected countries: the United Kingdom, Australia, New Zealand, and the United States. However, it should also be noted that Canadians have had a long and internationally renowned tradition of anti-stigma work, and have made significant contributions to this field.

Canadian anti-stigma efforts can be traced through the scientific literature to the early 1950s when a seminal study was conducted by a husband and wife team in a small Saskatchewan town (Cumming and Cumming 1955, 1957). The Cummings tried to improve the community's attitudes toward mental illness, both in terms of

residents' ability to interact with people who were mentally ill, and their sense of responsibility toward broader social issues surrounding mental health and mental illness. The program was intensive and complex (multi-pronged and multi-targeted) and used all of the methods available to health educators of the time. The project team worked with community members and local organizations to infuse positive mental health messages into every possible community activity, they created discussion groups, showed movies, employed radio and film advertisements, and distributed educational material in the form of brochures and pamphlets.

As the program grew in momentum and intensity, community reactions changed from interest, to anxiety, to outright hostility. It became apparent that people held fixed ideas about the causes of mental illness, the appropriate ways of dealing with those with a mental illness, and the correct amount of social responsibility to assume. Vigorous attempts to alter these views were not only unsuccessful, they resulted in the virtual rejection of the study team from the community. People did not want to have contact with mental illness on either personal or social levels, and they denied any relevance of mental health issues to their own personal lives. The "six-month educational program, in its all-out attempt to improve attitudes toward mental illness, produced virtually no change in the general orientation of the population either toward the social problem of mental illness or toward the mentally ill themselves" (Cumming and Cumming 1957, 88). The title of their 1957 publication, *Closed Ranks,* succinctly summarizes their main result; *O tempora, o mores!*

Twenty-three years later, in 1974, D'Arcy revisited this same Saskatchewan town to determine if public attitudes had changed in the intervening years. At that time, Canada was on the brink of major changes in the organization and delivery of mental health services and the major locus of care was about to change from the institution to the community. Elsewhere, public attitude surveys were

reporting more favourable attitudes toward the mentally ill, and this had sparked speculation that the extreme rejection of the mentally ill noted in the surveys of previous decades was a thing of the past. However, because the surveys had used different methods and instruments, interpretation of secular trends remained uncertain and largely speculative. Using the identical research instruments and survey methods originally used by the Cummings, D'Arcy was the first to document directly that "attitudes towards the mentally ill and recognition of psychiatric symptoms [had] changed little in the last quarter-century" (D'Arcy 1987, 289).

Over the next two decades, a second set of replication studies was conducted in Winnipeg confirming these results (Trute, Teft and Segall 1989). The first survey, conducted in 1976, questioned whether the Canadian public was uninformed about mental illness (simply lacking facts), or misinformed (holding false and prejudicial beliefs) (Trute and Loewen 1978). If the former proved to be true, then attempts to alter public opinion could focus almost entirely on education and literacy; if the latter, then educational approaches would have to be reconsidered in light of their limited ability to change behaviours. One of the important findings from the first survey was that attitudes toward the mentally ill were tied to levels of direct personal contact — the greater the contact, the more tolerant the attitude. This suggested that contact-based approaches that increased exposure to people with mental illness in roles that could be perceived by the public as being within normal limits might reduce stereotypical beliefs. Contact-based approaches have since been demonstrated to be effective in reducing stigma and improving social inclusion (Wolff 1997).

By 1986, Canada's community mental health movement was in full swing. Psychiatric institutions had been largely deinstitutionalized, there had been a concomitant increase in utilization of general hospital psychiatric units, and community-based treatment and rehabilitation services were emerg-ing. Despite these massive changes, the second replication study demonstrated virtually no improvements in socially rejecting attitudes toward individuals who had been identified as recipients of psychiatric treatment (Trute, Teft and Segall 1989). Increasing public awareness of human rights issues in Canada during that time did not indirectly liberalize views toward those with a mental illness. Results also confirmed the earlier findings (Cumming and Cumming 1957) that there were distinct differences between the public's views of situations involving social responsibility for mental health issues versus those involving interpersonal relations with the mentally ill, but neither had changed over time. The authors also confirmed that interpersonal acceptance toward those with a mental illness was associated with levels of direct personal contact, and they found that young people were more comfortable relating to people with a mental illness. They were more open to social contact and less socially rejecting, making them a potentially important target group for anti-stigma programs.

During the 1990s Alberta became the pilot site for the World Psychiatric Association's Open-the-Doors global program to fight stigma and discrimination because of schizophrenia. The program has since been rolled out in more than 20 countries and remains the only global anti-stigma effort in existence today (Sartorius 2004). The primary goal of the 1996 pilot program was to evaluate the effectiveness and feasibility of different approaches to stigma reduction in order to guide subsequent practices. A second goal was to test and refine the generic program development model that was to be used by countries wishing to join this initiative (Stuart 2002). In 2001, based on this work, the director of the Canadian Pilot Program was invited to address the 54th World Health Assembly Ministerial Round Table on the state of the evidence relating to stigmatization and human rights violations (Arboleda-Flórez 2001).

Results of community surveys conducted for the Pilot Program showed that the general public were

relatively well informed about schizophrenia (Stuart and Arboleda-Flórez 2001; Thompson *et al*. 2002). The majority could identify a biological cause and most were supportive of community-based treatment (Stuart and Arboleda-Flórez 2001). In addition, most believed that "loss of mind" was the most disabling of all handicapping conditions, and half said they would support increases in taxation in order to pay for better services for the mentally ill (Thompson *et al*. 2002). Yet, greater knowledge was not associated with more accepting attitudes, again suggesting that different mechanisms were at work with respect to levels of literacy versus stigmatized views. For example, those who reported working in a mental health agency, while more knowledgeable, were as stigmatizing as any other group (Stuart and Arboleda-Flórez 2001). Similar results have been reported in Toronto (Taylor and Dear 1981), and Quebec (Stip, Caron and Lane 2001). In Quebec, for example, half of those surveyed understood that schizophrenia was biologically based. Yet, schizophrenia still engendered feelings of incomprehension (36 percent) and suspiciousness (39 percent). Over half (54 percent) thought that people with schizophrenia were violent and dangerous. One in ten believed schizophrenia was an imaginary illness of the soul, or that it was incurable (Stip, Caron and Lane 2001).

The pilot program implemented a variety of different interventions, evaluated their effects, then developed guidelines based on the lessons learned (Stuart 2002). As predicted by earlier Canadian work (Cumming and Cumming 1957; Trute and Loewen 1978; Trute, Teft and Segall 1989) interventions that employed personal contact with people living with schizophrenia, particularly those targeting high school youth, demonstrated large improvements in knowledge, attitudes, and social-distance scores. Also successful was an attempt to change local structures that supported inequitable treatment, specifically emergency room policies and procedures for managing contacts involving people with schizophrenia. Guidelines were forwarded to the Canadian Council for Hospital Accreditation where

they were incorporated into national hospital accreditation standards (Sartorius 2004).

A literacy-based intervention that used radio advertising to try to reduce misinformation in the general public showed no change on any of the knowledge, attitude, or social-distance dimensions. This intervention was also the most expensive to implement and the most difficult to evaluate. An attempt to influence the local news by increasing positive newspaper stories about mental illness and schizophrenia was successful in meeting its stated objectives, but largely ineffective in terms of reducing misinformation. While significant improvements in positive news were realized, negative news stories grew at a faster pace, outstripping the positive stories in both number and size (Stuart 2002, 2003).

A final contact-based intervention — the play *Starry, Starry Night* — was not quantitatively evaluated but nevertheless appeared to have an important impact. While originally intended for health personnel, it has since been exposed to a wide range of audiences (scientific, professional, and lay) to depict the lived experience of schizophrenia. The 50 to 60 actors, who all have schizophrenia, unanimously report that the play has improved their self-esteem and their sense of mastery. Audiences who experience the play appear to be openly moved, and in the post-play discussions they report on the powerful impact of the performance and the extent to which it has altered their views of people with schizophrenia and changed their understanding of recovery.

LESSONS LEARNED IN STIGMA REDUCTION

Reflecting on the lessons learned from past Canadian research, current participation in the World Psychiatric Association's Open-the-Doors program, and considering the testimonial evidence contained in the Senate Committee's reports (Canada. Parliament. Senate 2004), the following ten lessons for stigma reduction are offered both to distil Canadian

experiences and to provide guidance for further policy debate.

- Aim for improvements in the lives of people with mental disorders and their families. Improvements in mental health literacy in the general public are inconsequential if they do not also translate into a greater sense of social responsibility and social justice, community tolerance, and social inclusion for individuals and families who live with mental disorders.

- Involve people with mental illness and their family members in all aspects of program development, evaluation, and communication so that programs address the most meaningful aspects of stigma and discrimination.

- Accept that education modifies literacy, and sometimes attitudes, but rarely behaviour — and keep in mind that real change is contingent on behavioural change.

- Programs that are modest in scope — that is, targeted to a specific audience; capable of delivering complex and emotionally charged interventions; and sustainable — enjoy a greater chance of success. Campaigns that are generic, that is, impersonal, literacy-based, targeted at the general public, short lived and expensive, are largely ineffective and discouraging for all involved. They may also impart the false message that psychiatric stigma and discrimination cannot be beaten.

- Recognize that there is no such thing as the general population when it comes to stigma reduction. One size does not fit all. Target programs to the needs of explicitly defined subgroups and deliver them in carefully focused ways.

- Think big, but start small. Target the things that can be controlled (such as local policies and practices) and leave alone the things that can't (such as negative news).

- Accumulate small successes. Not only do these provide momentum for program activities, they create a sense of possibility and prevent burnout. Accumulated successes also create a platform for sustainability and reinforce the message that stigma and discrimination can be beaten.

- Use the media *as allies in the process* rather than as objects of intervention or the sole means of transmitting messages.

- Build on the work of others in Canada, other countries, and internationally; cooperate, communicate, and coordinate.

- Contribute to Canada's store of best-practice knowledge; first through careful program development, then by rigorous self-evaluation, and finally through scholarly communication.

In summary, this paper is in response to the findings of the Standing Senate Committee on Social Affairs, Science and Technology as they pertain to the issues of stigma and discrimination of people with a mental disorder. Stigma perpetuates a cycle of impoverishment and disability, and is a key barrier to full citizenship for people with mental disorders and those closest to them. Stigma also retards mental health reform, system improvement, and mental health research. There is, as the committee correctly noted, a pressing need to implement anti-stigma interventions in Canada.

Canadians have over 50 years of experience in anti-stigma programming — perhaps more than any other country — and we have made significant contributions to the scholarly literature on this subject. We are well poised to implement any recommendations or policy initiatives the committee chooses to make designed to reduce psychiatric stigma and discrimination.

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