Implementing local projects to reduce the stigma of mental illness*

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Abstract. This editorial describes strategies used and the lessons learned in implementing two local anti-stigma projects. The WPA *Programme to Reduce Stigma and Discrimination Because of Schizophrenia* established projects to fight stigma in 20 countries, using social-marketing techniques to enhance their effectiveness. First steps at each site were to establish an action committee and conduct a survey of perceived stigma. Based on survey results, the action committees selected a few homogeneous and accessible target groups, such as employers, and criminal justice personnel. Messages and media were selected, tested, and refined. Guidelines are provided for setting up a consumer (service-user) speakers' bureau and for establishing a media-watch organization, which can lobby news and entertainment media to exclude negative portrayals of people with mental illness. Improvements in knowledge about mental illness were effected in high school students and criminal justice personnel. Positive changes in attitude towards people with mental illness were achieved with high school students, but were more difficult to achieve with police officers. Local antistigma projects can be effective in reducing stigma and relatively inexpensive. The involvement of consumers is important in working with police officers. Project organizers should be on the lookout for useful changes that can become permanent.

Efforts have been made since the 1950s to reduce the prejudice towards people with mental illness (Cumming & Cumming, 1957; Nunally, 1961). Despite these attempts, stigma (Hall *et al.*, 1993; Brockington *et al.*, 1993), discrimination (Sayce, 1998), and misconceptions about mental illness continue to be pervasive (O'Grady, 1996; Borinstein, 1992; Weiner *et al.*, 1988; Corrigan *et al.*, 2000; 2002; 2004; Link *et al.*, 1999; Thompson *et al.*, 2002). Citizen-driven not-in-my-backyard (NIMBY) campaigns obstruct the placement of residential facilities (Boydall *et al.*, 1989; Repper *et al.*, 1997). The perception of stigma by people with psychosis is associated with enduring negative effects on their self-esteem, well-being, mental status, work status, and income (Link *et al.*, 1997; Link, 1987). Public and professional opinions about mental illness adversely affect its detection and outcome (Hall *et al.*, 1994; Jorm, 2000; Link *et al.*, 1999; Stuart & Arboleda-Florez, 2001; Magliano *et al.*, 2004). Both the 1999 US Surgeon General's Report (NIMH, 1999) and the 2001 WHO World Health Report (World Health Organization, 2001) cite stigma as one of the greatest obstacles to the treatment of mental illness.

In the past decade we have seen an increase in the will to combat stigma. We have also seen the application of a new tool, social marketing, to this task. This editorial describes how two sites in the World Psychiatric Association (WPA) Programme to Reduce Stigma and Discrimination Because of Schizophrenia – Calgary, Alberta, and Boulder, Colorado – harnessed this tool to combat stigma.

SOCIAL MARKETING

Social-marketing campaigns have been used successfully around the world in AIDS prevention, smoking cessation, and many other causes (Rogers, 1995). Effectiveness is increased by audience segmentation – that is, partitioning a mass audience into sub-audiences that are relatively homogeneous and devising appropriately targeted promotional strategies and messages (Rogers, 1996). In developing such campaigns, it is useful to conduct a needs assessment that gathers information about the groups' cultural beliefs and the media through which they could best learn about the topic. The needs assessment may incorporate focus groups, telephone surveys, or information from opinion leaders.

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Specific objectives, audiences, messages, and media are selected, and an action plan is drawn up. The messages and materials are pre-tested with audiences and revised. The plan is implemented and, with continuous monitoring of impact, constantly refined (Rogers, 1995).

IMPLEMENTING LOCAL ANTISTIGMA PROJECT

The WPA global antistigma programme, launched in 1996 (Sartorius, 1997), established projects to fight stigma in 20 countries and created a process for setting up projects in local communities which follows these steps: establish a local action committee, conduct a survey of sources of stigma, select target groups, choose messages and media, and evaluate the impact of interventions, while continuously refining them.

Establishing a local action committee

The composition of the action committee is critical in establishing a local project. Committee members should include representatives of groups that the campaign is considering targeting; however, these groups will not be known when the action committee is formed. Therefore, the initial planning group should select committee members from walks of life that are likely to become target groups, such as the police, employers, or clergy, and add members later as needed. Some of the most valuable members of the action committee will be consumers (service-users) and family members, who have a first-hand understanding of discrimination. It is useful to include prominent citizens, such as legislators, on the committee. For example, when requesting a meeting with the editorial board of the local newspaper, the inclusion of someone with name recognition increases the impact of the request. An action committee should comprise ten to 20 members – neither so small as to burden members with too much work nor so big as to be unwieldy.

Selecting target groups

It is helpful to conduct a survey of local consumers, family members, and others to determine where stigma is seen to be prevalent – for example, in emergency departments or among employers. The action committee can use this information to select a manageable number of target groups, preferably no more than three. It is inadvisable to target the general population. To do so is expensive and unlikely to have a measurable impact. In the Calgary project, random pre-post telephone surveys revealed that a radio campaign targeted at the general public produced no change in attitudes toward or knowledge of mental illness (Stuart, 2002). Target groups should be homogeneous and accessible. For example, landlords are not an accessible group because they do not meet as a group or use a common media outlet. Employers are more accessible because the project can identify the largest local employers and target their human resource departments. The police are also an accessible group, because they receive regular in-service training.

Action plans

The action committee develops an action plan that includes specific goals and objectives for each target group. The goals might include, in increasing order of difficulty, developing awareness, increasing knowledge, changing attitudes, and changing behaviour – for example, reducing discrimination in housing. For a target group such as high school students, the goals might be to increase awareness of stigma, increase knowledge about schizophrenia, and reduce stigmatizing attitudes. To meet these goals, measurable objectives might include giving a presentation about stigma and mental illness to 50 percent of the students in the district, achieving 25 percent improvement in the average scores on mental illness knowledge and a 10 percent reduction in the average scores on social distance among participating students.

TARGET GROUPS

Working with schools

High school students were a popular target group in the WPA global antistigma programme; this group was selected by at least a dozen projects, from Calgary, Canada, to Ismailia, Egypt. The popularity of this target group has less to do with the likelihood that students will stigmatize people with mental illness and more to do with their ready accessibility and the opportunity to influence the attitudes of a coming generation.

Examples of messages that were used in the high school antistigma programmes in Calgary and Boulder include "No one is to blame for schizophrenia," "People with schizophrenia are *people* with schizophrenia," and "Watch your language" – that is, don't use derogatory terms to refer to people with mental illness. Media that

were used included speakers with mental illness, the Web page of the WPA programme (www.openthedoors.com), a teaching guide on schizophrenia (available on the Web page), and an art competition for students to produce antistigma materials.

The impact of a social-marketing campaign is increased if the target group receives the same message from different sources (the media multiplier effect) (Smith, 2002). In Boulder, interior bus advertisements reach a predominantly younger audience and are free for public-service announcements. The WPA project in Boulder installed several bus advertisements with antistigma messages. Cinema patrons are also predominantly younger people. The Boulder project ran slides with three different antistigma messages among the advertisements that preceded the main feature on 16 local cinema screens. One message read, "Don't believe everything you see at the movies: mental illness does not equal violence." Exit surveys revealed that 18 percent of cinema patrons recalled the content of at least one of the three messages displayed.

Outcomes from high school interventions have been positive throughout the WPA project. In Calgary more than 3,000 students participated in the intervention. Post-testing was conducted at different times, from minutes to weeks after the intervention, depending on the classroom. The proportion of students who answered all the questions about mental illness correctly increased from 12 to 28 percent on pre-post testing and the proportion, who expressed no social distance between themselves and someone with schizophrenia increased from 16 to 30 percent (Stuart, 2002). In Vienna positive changes in attitudes were evident three months after the intervention (Ladinser, 2001). At three sites in Egypt students were tested about their knowledge about schizophrenia and its treatment before and after the intervention. The students' scores doubled after the intervention, and the proportion of students who believed that someone with schizophrenia would be likely to commit a crime decreased from 56 to 29 percent (El-Defrawi *et al.*, 2001). In Leipzig, Germany, students were tested about their attitudes toward a person with schizophrenia; scores improved substantially during a three-month follow-up in the group of 90 students that received the intervention but not in the control group of 60 students (Schulze *et al.*, 2001).

Working with the criminal justice system

Criminal justice personnel are under-recognized partners in the management of mental illness. The police bring people who are acutely disturbed into care or protective settings. Jail officers struggle to manage people with acute psychosis in environments that are totally unsuited to the task. Judges wrestle with the disposition of mentally ill offenders. Probation officers supervise people with mental illness, even though the officers do not have access to consultation about the person's capacity to respond to directives. Yet there are few programmes that attempt to provide criminal justice personnel with the education necessary to perform these essential parts of their jobs. For this reason, the Boulder antistigma project, and other WPA programme sites, selected criminal justice personnel as a target.

Police training. Mental health professionals, consumers, and police officers collaborated in developing an, eight-hour training course, which was pilot tested with seasoned officers and rookies in the county's largest city (population 100,000). Applying lessons learned from pre-post testing in the pilot programme, the project undertook the training of the entire police force for the county of Boulder and the cities within the county (total population 300,000). The training was presented by psychiatrists, consumers, and their family members. The content included the features, course, treatment, and outcome of psychotic disorders; myths about schizophrenia; the diagnosis and treatment of childhood disorders and disorders of the elderly; the diverse characteristics of people who attempt suicide; and a discussion of why people with psychosis should not be kept in jail. The classes discussed why people with borderline personality disorder are often not admitted to a hospital. This topic is important if the training is to be successful, because police officers everywhere are likely to complain about bringing someone in for evaluation after a suicide attempt, only to learn later, as commonly phrased, "She got home before I did!"

Pre-post testing of the officers conducted immediately before and after the training, revealed no improvement in attitudes toward people with psychosis, but it revealed a 48 percent improvement in scores of knowledge about adult and child mental disorders. The proportion of officers who held inaccurate beliefs about the causes of schizophrenia fell from 24 to 3 percent, but another misconception scarcely changed. The proportion who held a mistaken belief about the usual behaviour of people with schizophrenia only fell from 82 to 71 percent. After training, 71 percent of the officers still believed one or more of the following statements: people with schizophrenia are always irrational, much more likely to be violent than the average person, or usually unable to make life decisions. Officers retained these beliefs, even though they heard a presentation by a quietly eloquent, middle-aged

woman with schizophrenia who was working full-time as a university library supervisor.

We subsequently realized that police encounters with people with psychosis nearly always occur when the person is acutely disturbed, and officers have little opportunity to meet people with schizophrenia who are working, in stable relationships, or rarely hospitalized. We concluded that police training must intensively expose officers to people who have recovered from psychosis if it is to effect attitudinal change. A model programme that uses consumers to provide police training has been established in the WPA antistigma project in Kent, England (Pinfold, 2001).

Judges, attorneys, and probation officers. Psychiatrists, people with mental illness, and family members provided three training sessions on adult disorders and one training session on child disorders to judges, attorneys, and probation officers (approximately 12 in each category). Nearly all the county judges attended. A pre-post test conducted directly before and after the training revealed that judges' accuracy of knowledge about schizophrenia improved from 47 to 74 percent, and some judges reported immediate changes in sentencing practice. After the training sessions were completed, the judges requested two more training sessions on juvenile disorders.

SETTING UP A CONSUMER SPEAKERS' BUREAU

A speakers' bureau is valuable for addressing students, police, and other groups. It often comprises people who have experienced mental illness, family members, and a mental health professional whose function is to answer factual questions – for example, what causes schizophrenia? People with mental illness can react to the stress of public speaking by experiencing an increase in symptoms shortly after the event. To minimize this possibility, consumers with good tolerance of stress should be selected. They should be gradually introduced to speaking in front of audiences by first observing and then speaking briefly until they can participate fully without experiencing stress. Speakers should be debriefed after each presentation to learn what they found stressful. Several speakers should be trained so that the demand on any one person is not too great.

Speakers who are consumers demonstrate the reality of recovery, generating optimism and compassion. A study conducted in Innsbruck, Austria, revealed that high school students addressed by a psychiatrist and a consumer reported significant changes in social distance attitudes, whereas those who were addressed by a psychiatrist and a social worker did not (Meise *et al.*, 2001). Other research has indicated that previous contact with someone with mental illness decreases stigma and fear of dangerousness (Link & Cullen, 1986; Penn *et al.*, 1994). Consumers can talk about discrimination in employment, housing, and law enforcement, but should try to avoid generating defensiveness in the audience.

SETTING A MEDIA-WATCH GROUP

Local and national advocacy groups can lobby news and entertainment media to exclude negative portrayals of people with psychosis. Such groups are known as "stigma-busters" or "media-watch" groups. A local antistigma project can establish the media-watch function in several ways. Members can inform national media-watch organizations about negative portrayals that are distributed nationally, respond to calls to action from national advocacy groups, and contact local media outlets about stigmatizing messages.

National media-watch bodies in the United States have become quite effective. The National Stigma Clearinghouse, which was begun in 1990 by the New York State chapter of the National Alliance for the Mentally Ill (NAMI), collects examples of negative portrayals of people with mental illness from a variety of US media. Staff write or phone the journalists, editors or others responsible for the negative portrayal, explaining why the material is offensive and providing accurate information about mental illness. In one instance the Clearinghouse was successful in getting DC Comics to change the story line that dealt with Superman's death, so that his killer was no longer "an escapee from an interplanetary insane asylum." NAMI has also used its national membership effectively to combat stigma. In 1999, in response to the airing of the TV series *Wonderland*, in which mentally ill people were seen committing numerous violent acts, NAMI coordinated a mailing to ABC and the show's commercial sponsors. The programme was pulled from the air after two episodes, even though 13 had been filmed.

Local media-watch groups do not need to be large or complex. One or two coordinators can establish links to a broader group of members who report stigmatizing items. The coordinators forward items of national scope to a national media-watch group or respond directly to a local newspaper or business about local items. A gradual escalation approach is generally effective. Begin with a polite request, perhaps suggesting that the stigmatizing reference was inadvertent. A positive response should be rewarded with a letter of thanks. Often those guilty of the offence are appropriately concerned and may later

become supporters of the media-watch group. If the offender is unresponsive, increasing pressure can be applied, such as writing a letter for publication in the local newspaper (Wahl, 1995).

FUNDING AND SUSTAINABILITY

Attempts to influence the general public through mass advertising are expensive and unlikely to prove effective, but targeted interventions, such as police training and classroom presentations, can be conducted and assessed with modest expense. Total expenditures during the first three years of the Boulder project were less than $10,000.

A local campaign cannot run forever (three years is a reasonable length of time) but permanent structures and partnerships can be developed. On the basis of experiences in Boulder, Calgary, and elsewhere, these might include changing the high school health curriculum to include mental illness, adapting school diversity programmes to include education about mental illness, forming a consumer speakers' bureau, creating a media-watch group, and changing institutional policy, such as emergency department procedures for dealing with people with mental illness (Thompson & Bland, 2001).

The project director should evaluate which components of the campaign will require ongoing funding and find support for these elements. Local advocacy groups or agencies may be willing to assume responsibility for some components.

CONCLUSIONS

Local antistigma projects should involve a broad array of community representatives in the planning and action committee. They should focus on a few specific target groups in which a change in knowledge, attitudes, or behaviour would be likely to reduce discrimination and improve the quality of life of people with mental illness. The project should aim to establish some permanent changes, which will allow sources of stigma to be monitored and/or modified on an ongoing basis. Attempts to target the general public are likely to be expensive and ineffective and are not encouraged.

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