

A Meeting of International Mental Illness Stigma
& Discrimination Leaders

June 23^d & 24th, 2009

The Carter Center

With thanks for the support and participation of the National Institute of
Mental Health

national programs in different countries (<http://www.openthedoors.com>; see attachment II). Dr. Sartorius also reported on the developments in Japan where the Japanese Psychiatric Association decided to abandon the word used to describe the diagnosis of schizophrenia and replace it by a word that has a less unpleasant connotation. A first result of this change was that psychiatrists found it easier to convey the name of the disease to their patients and the proportion of those who did so increased from one to five or six in every ten patients.

Evaluation of Open the Doors campaigns revealed that targeting all mental health conditions may impede anti-stigma efforts in some ways. By clumping all conditions together, mental illness may take on the image of schizophrenia with attributions of violence and aggression. It is important to target specific illnesses, such as depression and anxiety, when developing anti-stigma initiatives.

Canada - Mental Health Commission of Canada – Anti-stigma/anti-discrimination initiative

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Lessons learned from previous and current campaigns

The stigma experts discussed the importance of

Use social networking online media	Using new and emerging media as a resource for creating social and cultural change would expand the reach of programs.
Include other chronic conditions	Eliciting input and studying the models of other chronic illnesses

Changes in Stigma Associated with Mental Illness - What has changed over the past ten years?

In the past ten years, efforts within the mental health field have been shown to be both effective and detrimental in reducing stigma and discrimination towards individuals living with a mental illness. Previous research has shown that attitudes towards the condition of mental illness have become more open and accepting in some ways; however, perceptions of violence and fear still taint the image of recovery and perpetuate stigmatizing attitudes and discrimination.

The concept of a “disease like any other” has not been very effective in changing the cultural context of stigma in the United States. In particular, while advancements in neurological studies have increased our ability to determine genetic factors related to mental illnesses, this research has suggested that biological emphasis may actually impede anti-stigma efforts because genetic etiologies imply permanence and perpetuate discriminatory attitudes towards individuals living with a mental illness. Furthermore, an exclusive focus on biological causes undermines efforts to change unsupportive social and physical environments that adversely affect mental health (e.g., lack of good parenting skills; poverty; living in conflict/war-prone areas).

Dr. Bernice Pescosolido mentioned that, in the last ten years, people, specifically younger individuals, have become more willing to talk to others and family members about mental illnesses and to seek non-medical mental health professionals (psychologists, counselors, and social workers). However, in many ways, the perception of mental illnesses has become more negative because the association with violence has increased four-fold. People are more likely to view mental illnesses as inevitably linked to violent acts than they were in the 1950's.

A public stigma study across 15 countries revealed that in most countries, mental illnesses are consistently associated with fear and danger. In developing countries, stigmatizing attitudes are more widespread across various illnesses, and are not necessarily targeted towards individuals with mental illness.

U.S. population agreed that people with mental illness could lead normal lives with the help of treatment, but those who were less educated and younger tended to disagree. A small percentage of individuals believe that people are generally caring and sympathetic towards people with a mental illness.

The group agreed that this type of survey research is imperative in shaping future anti-stigma efforts. The data allows the field to target these efforts towards specific groups of people as well as specific concepts and ideas.

Dr. Heather Stuart remarked that, at this point, the research field knows how to change knowledge and attitudes, but only on the policy. In terms of changing behavior, the field has not made any advancement in the past ten years. In order to advance the reduction of stigma, it is important to develop partnerships and alliances with other invested groups, particularly forming a stronger partnership with consumers.

In respect to advancements in research, the role of consumers has significantly changed in the past ten years. Consumer experience should have played a more significant role in recent efforts. However, despite these improvements, there is still a need to increase the role of consumers. The research field should continue to develop without this crucial aspect. One of the best ways to incorporate the consumer component of research is in qualitative research.

In Canada, there has been a shift from a scientific paradigm to a public health approach where researchers are now focusing on the role of the consumer, looking at qualitative and experience data to drive anti-stigma efforts. There has been a rise in anti-stigma activities at both the local and national level. However, the challenge is coordinating these efforts to move in the same direction.

Dr. Sue Estroff noted that there are recurring conditions that characterize treatment of those with stigmatized conditions that cannot be left out of the conversation. These include: confinement and containment, fear, allure, coercion and force. Forced and involuntary treatment is a direct indication of a failed system. There have been some positive advancements in the field, such as the passage of parity, but the economic crisis has taken a considerable toll on mental

from non-medical mental health professionals	explanation
Belief that normal lives are possible	Belief that the general public is uncaring and unsympathetic

Establish consensus for a benchmark on the current status of stigma and discrimination

The group proposed the following guidelines/benchmarks on the current status of stigma and discrimination:

Tangible and easily identified	Benchmarks should be tangible and easily identified and include defined measures such as employment and housing.
Culturally significant	From an international standpoint, these benchmarks should be culturally significant, but comprehensible to the international stigma community.

The group proposed the following methods to reduce the stigma of mental illnesses moving into the future:

Develop a tag line for mental health	The anti-stigma mental health community needs to develop a new tag line or “strap line,” one that promotes a positive framework for approaching mental illness. The anti-stigma mental health community can explore opportunities to use the latest techniques and tools in social marketing to impact stigma.
Change in the representation of mental illnesses	Violence still serves as the biggest barrier to reducing stigma. It undermines progress that has been made. There is a need to change the face of mental illness from violence to the person who is going to work everyday, or contributing to their families. There may also be opportunities with respect to addressing the comorbidity of mental illness and chronic disease that affects millions of people.
Change the image of treatment	The current image of treatment has not been helpful in reducing stigma and discrimination. There is an evident lack of focus on the successful recovery of those who live with a mental illness. But treatment and recovery are not the same thing, and at times they can be at odds. Most individuals are not getting adequately financed, effectively delivered treatment.
Highlight success stories	Media and journalists can and do play a

	crucial role in reporting on “success stories,” but the group did express concern that these stories may not be “top reads.”
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Analysis of Stigma and Discrimination Research - What are the gaps in research from the past ten years?

In order to better understand how anti-stigma efforts should move forward in the future, the group discussed research from the past several years and identified which work had been most effective in guiding on-the-ground anti-stigma efforts. Research on the experiences and accounts of both consumers and non-consumers has greatly helped to inform the field on the current status of stigma and discrimination. By defining stigma and its multiple components, the field has been able to more accurately research stigma and identify areas of focus or need (e.g., Elimination of Barriers Initiative); however, significant gaps in research remain.

Dr. Otto Wahl briefly described components of stigma:

- Stereotypes
- Negative associations
- Cognitions
- Power and authority

More research should focus on the contact hypothesis, looking at how contact with individuals living with a mental illness improves stereotypes. The most effective measures include: social distance measures- these measures have been translated into a variety of forms, are easy to use, and provide consistency across the field; and measures that reflect different aspects of stigma.

The group briefly reviewed Dr. Patrick Corrigan’s work on defining stigma (See Attachment II) and addressed the difficulty of measuring stigma. Currently, there is no consensus throughout the field on the definition of “stigma.” For validity reasons, this is a serious area of concern that must be addressed.

Three factors were identified that likely influence which measures are most likely to be utilized: whether or not the measurement is easy, the cost of the measurement, and whether the measurement is not heavily influenced by social desirability.

Identified gaps in research to inform development of future research agenda

The following significant gaps in research were identified by Dr. Wahl and Dr. Corrigan:

^{§§} Corrigan, P.A. Toolkit for Evaluating Programs Meant to Erase the Stigma of Mental Illness
Institute of Technology, 2008.

Demonstration of cause and effect relationships *By changing knowledge and attitudes, can behavior be changed consequently?*
 Examination of contribution of mental health professionals to perpetuating or reducing stigma *How can mental health professionals help to reduce stigma?*
 Exploration of attitudes of children *How do children perceive mental illnesses?*
 Increase in evaluation research *How effective are the campaigns and initiatives?*

Challenges to Addressing Gaps in Research

These gaps in research have not been addressed for several reasons, the most obvious being a lack of funding. In addition, the field as a whole has had difficulty with the consistency of measures and lacks an identified outlet for information exchange—e.g., no journal for stigma research that can serve as an open forum. The group expressed a need to possibly create a technical support center to support the research of different initiatives. The suggested center would be in coordination with or build on the work of the ADS Center previously mentioned. The ADS Center provides materials for schools, businesses, and advocacy groups. Furthermore, the lack of professional encouragement to increase interest in students to focus on stigma research instigates a need to focus on a younger generation of researchers in the field.

Key Components of an Agenda for Future Stigma Research and Anti-Stigma Initiatives - What should be achieved in the next ten years?

After lengthy discussions and review of expectations and data, the group collectively developed a plan for future action (See Attachment III). The group discussed key areas in which future research should focus based on the gaps identified earlier. Priority items were outlined in order to guide action items for the group to address, and a final plan of action was developed to create tangible deliverables for the group to pursue.

Final Plan of Action:

1. United States to host the 6th international stigma conference:
 The group agreed that after the next international stigma conference, a conference should be held in the United States, possibly hosted by the Carter Center Mental Health Program with support from other organizations such as NIMH, SAMHSA, or CDC. In 2001, the Fogarty International Center and other NIH institutes and centers hosted an international conference across disease entities titled “Stigma and Global Health: Developing a Research Agenda”; and a request for applications was subsequently issued. However, the United States has yet to host the International Stigma Conference; this would be a way to make stigma and discrimination a national focus and recruit participation outside of the mental health field.
2. Convene other organizations outside the mental health field with which to partner and collaborate:

The group reiterated the importance of reaching out to non-mental health organizations, such as the Rotary Club organization, business leadership networks, and National Education Association. These are examples of groups on the ground that have had experience dealing with mental health in the

Attachment I
Meeting of Stigma Experts
Attendees

Patrick Corrigan, PsyD
Professor of Psychology
Illinois Institute of Technology

Benjamin Druss, MD, MPH
Rosalynn Carter Endowed Chair in
Mental Health
Rollins School of Public Health
Emory University
Mental Health Task Force Member

Sue Estroff, PhD
Professor, Department of Social
Medicine
University of North Carolina, Chapel
Hill

Anthony Jorm, PhD, DSc
Professorial Fellow
ORYGEN Research Centre
Centre for Youth Mental Health
University of Melbourne

Bernice Pescosolido, PhD
Director
Indiana Consortium for Mental Health
Services Research

Norman Sartorius, MD, PhD
Former Director, Division of Mental
Health, WHO
Professorial appointments at the
Universities of London, Prague, St.
Louis, and others
Illinoisne

Attachment II

Current Stigma Research, Surveillance, and Anti-Stigma Campaigns Under Discussion

Past and Current Anti-Stigma Campaigns

International Campaigns

beyondblue - Australia

beyondblue is a national depression initiative focused around five priorities:

- Increase community awareness and reduce stigma
- Provide information to consumers and caregivers
-

stigma and discrimination towards people living with a mental illness via a three-pronged approach:

1. Public education outreach and peer-support promotion based on social marketing-type research.

- “What a Difference a Friend Makes” is a national campaign that addresses the first prong by reaching out to individuals between the ages of 18 and 25. SAMHSA developed the social marketing-type research and in-depth surveys to understand how best to address their target group. The main focus is encouraging individuals to be supportive towards friends and family members living with a mental illness.
- SAMHSA has done extensive research and evaluation to ensure the effectiveness of the “What a Difference a Friend Makes” campaign including in-depth focus group research and message testing with the target audience, NIMH study of the effectiveness of the TV PSAs to reduce stigma with the target population, pre-wave and post-wave ad recognition and impact surveys, a survey of PSA director attitudes toward the issue and the specific materials, media monitoring, web site tracking, and materials distribution measures. The campaign also partnered with the Center for Disease Control and Prevention (CDC) to assess stigma through annual national surveys.
- Through the outstanding work of its local partners and supporters including colleges and universities, SAMHSA’s CMHR has distributed over 700,000 “What a Difference a Friend Makes” brochures. The brochure continues to be one of the most requested items from the SAMHSA catalogue of materials.
- The CMHR has developed two new phases of the “What a Difference a Friend Makes” campaign. Multicultural PSAs have been developed based on the campaign and designed with specific messaging and materials for young adult African Americans, Chinese Americans, Hispanics, and Native Americans. These materials will be launched in the Fall of 2009. Also, a new social networking element has been developed for the existing campaign website along with several new

interactive videos, banners, and ads and is also expected to launch in Fall 2009.

2. Voice Awards program that involves consumers, writers, and producers in the entertainment and media industries to recognize accurate and dignified depictions of mental illness.

- The Voice Awards program acknowledges writers and producers of films and TV who have accurately portrayed mental illness in their work. In addition, the program honors consumers and individuals who have been active in fighting stigma and discrimination in their communities and on a national level.

3. Technical assistance center for efforts to promote acceptance, dignity, and social inclusion.

- The Center to Promote Acceptance, Dignity, and Social Inclusion (ADS Center) is a technical assistance center to address stigma and discrimination.

- Contact strategy activities include speakers' bureaus, film project photovoice projects, publishing recovery stories, developing PSAs, toolkits, internet games and interactive elements, etc. Chris Marshall shared one of the products, a book, titled *Fire Walkers*, composed of recovery stories from in-depth interviews with mental health consumers, that was used to educate the community. The group acknowledged that this type of outreach through a narrative approach could be extremely beneficial for improving the face of mental illness and what recovery could mean.

CDC Stigma Survey Research

CDC and SAMHSA - Current Stigma Research

The Centers for Disease Control and Prevention in collaboration with SAMHSA developed baseline stigma measures to study public attitudes on stigma and discrimination. The agencies collaborated on two studies. One study, conducted in 2005, sought to collect state-specific stigma estimates. Thirty-five states, D.C. and PR collected data using the 2005 BRFSS Mental Illness and Stigma module which included two stigma items.

- o Treatment can help individuals with mental illness lead normal lives

- People are generally caring and sympathetic towards people with a mental illness.

Results:

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5. Courtesy stigma- the stigma that befalls associates of

Attachment III

Final Action Plan and Next Steps

After reviewing the objectives for the meeting, the group developed a Final Action Plan and Next Steps. These include areas for future research, priority items upon which to develop deliverables, and five deliverables to be executed by the participants of the meeting.

Final Plan

Maintaining Focus on Key Overarching Issues- Consumer engagement at all levels and exploring ways in which the deliverables translate to mental health system reform in real world settings.

United States to host the 8 international stigma conference

Convene other organizations outside the mental health field with which to partner and collaborate

Create online forum to provide resources and information on international efforts, both research and applied

Create a research toolkit

Communicate priorities within and outside of stigma field

Priority Items

- Focus on consumer empowerment and involvement with family members and caregivers
- Target research towards needed areas including personal accounts and experiences and reaching out to new researchers
- Inclusion of policy initiatives in congressional briefing on BRFSS continued support of the efforts by the CDC on stigma surveillance
- Coordinate public response to violent acts associated with mental illnesses
- Identify and create a toolkit of the five components of a successful campaign
- Build capacity in research
- Create a stigma research journal
- Secure funding to support new students and young professionals so as to engage upcoming generation

Future Research Considerations

Unwrap labeling processes and identify triggers

Create consistent measurements

Engage consumers in measuring their experiences and utilize direct testimonies

Incorporate use of direct observation

Explore stigma developmentally

Focus on enhancing positive behaviors rather than only on stopping negative ones