THE CARTER CENTER
MENTAL HEALTH PROGRAM

Waging Peace. Fighting Disease. Building Hope.

A Meeting of International Mental Illness Stigma & Discrimination Leaders

June 23rd & 24th, 2009
The Carter Center

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

Executive Summary
Mental illnesses impose some of the greatest disability burdens worldwide. Major depression is one of the most costly diseases socially, personally, and economically, and is ranked as the leading cause of morbidity and lost productivity in the United States. It often co-occurs in people with many other highly prevalent illnesses and disorders such as cancer, heart disease, and arthritis, but is often missed and goes untreated. Despite an increase in knowledge and effective treatments for mental illnesses, these health problems remain under-reported and unrecognized. Stigma remains the single greatest barrier for those seeking treatment. The failure of healthcare systems to adequately recognize and address the mental health needs of the public has perpetuated discriminatory attitudes towards those living with untreated or sub-optimally treated mental illness who continue to experience mental illness symptoms that interfere with their daily lives, and sometimes those of their caregivers, friends, and employers.

The Carter Center Mental Health Program has identified stigma and discrimination against people living with a mental illness as a key focus area for improving the lives of those with mental health problems and improving mental health systems as a whole. In an effort to assess the current status of stigma and to explore areas for improvement, a *Meeting of International Mental Illness Stigma & Discrimination Leaders* was held on June 23-24, 2009 at The Carter Center with the support and participation of the National Institute of Mental Health (NIMH).

The purpose of this meeting was to focus on two areas of importance in the field; one being the need to identify **key stigma measurement challenges**, and the second to discern **where the field should go from this point** with goals to identify the **next steps** to improving future anti-stigma initiatives. The following four objectives were outlined to facilitate discussion among the participants:

- To discuss the status of anti-stigma campaign efforts over the past ten years;
- To identify if and how the stigma associated with mental illnesses may have changed over the past ten years;
- To analyze stigma and discrimination research from the past ten years and identify any gaps; and
- To identify the key components of an agenda for future stigma research and anti-stigma initiatives, and what role The Carter Center might play in facilitating next steps.

After reviewing discussions from the day and a half meeting, the group leaders collectively developed a plan for future action (See Attachment III). The group discussed key areas in which future research should be focused, identified priority areas upon which to target future actions, and developed a final plan of action in which tangible deliverables were identified for the group to pursue.

The meeting participants included mental health consumers, leading international researchers in the field, federal program directors, journalism fellowship advisory board members, university professors, and mental health professionals (See Attachment I). The following document summarizes the group's discussions surrounding the four

aforementioned objectives, and the collective recommendations for future plans and next steps.

Status of Past and Current Mental Illness Anti-Stigma Campaigns - What has been done in the past ten years?

International Campaigns
Australia
Dr. Anthony Jorm presented current anti-stigma efforts taking place in Australia. An evaluation of *beyondblue: the national depression initiative* (http://www.beyondblue.org.au; see attachment II), revealed that when awareness increased of the discrimination experienced by individuals living with depression, openness about depression increased among the population in general. States participating in the campaign demonstrated greater public openness about depression and had higher rates of reporting that family or friends had depression, but were less likely to feel that others would be accepting of individuals with a mental illness.[*] Young individuals who were exposed to the campaign were less likely to see depression as a personal weakness.[†]

A unique approach to the collaboration and participation of non-mental health organizations in anti-stigma efforts is found in the "Australian Rotary Health" community forum program. This program was launched collectively by individual Rotary Clubs to hold community, workplace, and school forums to support research in mental health and to raise awareness within the community. This approach is unique in that it is led by a community organization rather than a mental health organization, which allows for its messages to better reach the general public.

The Mental Health First Aid Course (See Attachment II), an initiative that uses the conventional model for first aid training, has proven to be effective in reducing some aspects of stigma and stigmatizing attitudes, and in increasing mental health literacy among those taking the course.[‡] This unique approach to working with the public could be beneficial in reducing stigma in numerous public settings. Research has shown that merely educating the public on mental illness may actually increase some elements of stigma, but that by supplying a skill that helps in handling a crisis situation is more useful and effective.

Programs Involving Several Countries – World Psychiatric Association
Dr. Norman Sartorius presented a summary of lessons learned during the multicentric international Open the Doors Program of the World Psychiatric Association and during

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[*] Jorm, A.F., Christensen, H. & Griffiths, K.M. (2006). Changes in depression awareness and attitudes in Australia: the impact of *beyondblue: the national depression initiative*. *Australian and New Zealand Journal of Psychiatry*, 40, 42-46.

[†] Jorm, A.F. & Wright, A. (2008). Influences on young people's stigmatising attitudes towards peers with mental disorders: A national survey of young Australians and their parents. *British Journal of Psychiatry*, 192, 144-149.

[‡] Kitchener, BA and Jorm, AF. Mental Health First Aid: An international programme for early intervention. *Early Intervention in Psychiatry* 2008; **2**; 55-61

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 campaign 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
The 10-year anti-stigma/anti-discrimination initiative launched by the Mental Health Commission of Canada will begin with a focused effort centering on two groups: youth ages 12-18, and health care professionals. Key to the development of the plan is a coordinated effort between consumers, researchers, and stakeholders. Parallel to the initiative, the commission will work to build a research knowledge base that can be utilized by professionals to inform other activities. Additional projects include a best practices network that provides evidence-based methods and processes to the field.

USA Campaigns
SAMHSA "Campaign for Mental Health Recovery"
SAMHSA's Campaign for Mental Health Recovery (CMHR; http://www.whatadifference.samhsa.gov/) is a comprehensive effort to address the negative attitudes, beliefs, and behavior associated with mental illnesses and to promote recovery, acceptance, and social inclusion for individuals with mental health problems. The CMHR has three main components: a series of public service announcement education campaigns; the Voice Awards program; and the Resource Center to Promote Acceptance, Dignity, and Social Inclusion Associated with Mental Health ("ADS Center"), a national technical assistance center.

Before the CMHR was launched, SAMHSA developed an eight state education and awareness campaign "Elimination of Barriers Initiative" (EBI) to test social marketing strategies and develop an evidence base for a national effort. Many lessons were learned from the EBI however the main findings were to use a multifaceted approach that employed proven strategies to counter stigma including a public education campaign, an awards program, and community level programs to promote interpersonal contact with people with mental health problems. A guide was published to report this information titled "Developing a Stigma Reduction Initiative" with extensive details on how to create a successful campaign.

SAMHSA partnered with the Advertising Council, Inc. to produce the first phase of the CMHR public education PSA campaign entitled" What a Difference a Friend Makes." The campaign targets young adults and encourages them to provide support to a friend who is experiencing mental health problems. Friends and family members by a vast majority are first points of contact for people experiencing mental illnesses and that initial contact and ongoing support is crucial to recovery. The campaign distributed multiple television, radio, print, and interactive PSAs nationwide to over 30,000 media outlets.

From the CMHR launch of the "What a Difference a Friend Makes" PSA campaign in December 2006 through March 2009 the CMHR has received a total of over $76 million dollars worth of donated advertising. In the second quarter of 2008 the CMHR ranked in the top 5 of the Ad Council's over 60 PSA campaigns, garnering over $21.5M worth of donated media in April, May, and June 2008 alone.

Since the launch, the website has had over 20 million hits and 1.4 million total visits. The site continues to average about 1 million hits and 50,000 visits per month. The average length of a visit to the Web site in 2008 was over 8 minutes per visit, significantly longer than the industry standard.

The Voice Awards program uses the reward strategy to encourage the use of respectful, dignified, and accurate portrayals of people with mental illnesses in the entertainment industry. Each year in Los Angeles, the Voice Awards are given to writers and producers of television and film who counter stigmatizing images of people with mental health problems with accurate depictions in their work. The Voice Awards also recognize individuals with mental illnesses who have led efforts to raise awareness and understanding of mental health problems and promoted social inclusion.

The ADS Center manages the interpersonal contact strategies for the CMHR and provides expert guidance on effective tools to counter the negative attitudes, beliefs, and behavior associated with mental illnesses. The ADS Center also produces a series of expert presentations and publications on reducing stigma and discrimination. This includes a state award program that provides financial awards to consumer-run organizations to support the "What a Difference a Friend Makes" campaign by developing contact strategies and implementing them to reach as many people as possible in the community.

Chris Marshall noted that future directions for SAMHSA's CMHR public education efforts include looking at the relationship between trauma and mental illness, the economic downturn and mental health impact, and launching the "10 by 10 Wellness Initiative", aimed at decreasing early mortality for people with mental illnesses by ten years over ten years. A recent study supported by SAMHSA revealed that people with mental health problems served by the public mental health system die on average 25 years earlier than the general population in many cases from preventable medical conditions. [§]

[§] Colton, C. and Manderscheid, R. Congruencies in Increased Mortality Rates, Years of

Lessons learned from previous and current campaigns

The stigma experts discussed the importance of involving the consumer perspective in the development and implementation of anti-stigma campaigns. The way to truly target stigma is to directly approach consumers and their family members and ask them about their experience. The field cannot assume that it knows what is best for these individuals. No progress can be made by simply "educating" them using an imposed formula. This new approach brings light to voices that have never before been heard or studied and can be a valuable asset to future areas of research and campaigns.

Furthermore, efforts should be made to promote the perception of a whole person and target the self-stigma often experienced by consumers. By improving the experience of competence in mental health consumers, self-stigmatizing attitudes can be greatly reduced and a sense of independence, self worth, and autonomy can be instilled in consumers.

Three key components for successful anti-stigma campaigns were identified by the participants. These components are based on evaluations of previous campaigns:
- Focus on positive actions rather than on what the public should not do;
- Plan for long-term sustainability of the project; and
- Build evaluation processes that are established at the beginning of a campaign rather than in retrospect.

In addition, the group outlined key lessons learned from past campaigns:

Lessons Learned	Discussion
• Involve non-mental health entities	By identifying the needs of non-mental health parties, anti-stigma efforts can infiltrate and form partnerships with these parties and organizations that might hold stake in the mental health community. Examples of these groups include Rotary Clubs, the National Education Association, and business leader networks.
• Build on previous successful models	Similar to the Australian initiative, building on models that work (*e.g.* first aid approach) could help the field to develop effective initiatives.
• Define target groups	Rather than focusing on the broader population, campaigns targeting specific groups (*e.g.*, specific illnesses, mental health professionals) would be beneficial.

Potential Life Lost, and Causes of Death among Public Mental Health Clients in Eight States. *Preventing Chronic Disease*, 2006.

• 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 would help to improve future anti-stigma efforts.
• Identify needs of target groups	Focusing on the needs of specified target groups and refraining from trying to "educate" them is important.
• Change the image of treatment	The image of treatment is too negative and often fails to relay the message that recovery is possible. Treatment should be evaluated not only by standard outcome measures, but also by acceptability, accessibility, and non-stigmatizing aspects. Treatment is one aspect of recovery, and it should be valued as an integral part of recovery while acknowledging that recovery encompasses a wide range of elements.
• Change attitudes and behavior	Attitudes and behaviors address two separate aspects of stigma. Therefore, focus should be put towards changing both.
• Focus on high prevalence disorders (*i.e.,* depression and anxiety)	By focusing on high prevalence disorders, campaigns are of greater personal relevance to the community, promoting the idea of "us" rather than "them."
• Shift the focus to consumers and families	In order to appropriately look at stigma, a shift must occur in the field from focusing on the treatment recommendations of mental health practitioners to focusing on the experiences and ideas of consumers and family members.
• Improve the role of mental health professionals	There is a need to work with mental health professionals to adopt appropriate mental health language, emphasizing the consumer's self-esteem during treatment and selecting non-stigmatizing treatments (*i.e.,* treatments without visible side effects, rapid in onset, applicable in general medical settings or in outpatient facilities).

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 associations 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 (*i.e.,* 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 a mental illness, whereas in developed countries, stigmatizing attitudes are narrowed down to specific illnesses (*i.e.* mental illnesses).[**]

PSAs have been effective in positively changing stigmatizing attitudes when incorporated into anti-stigma campaigns, but there is little support for the use of PSAs in these initiatives.[††]

Rosemarie Kobau reported that preliminary findings from the most recent stigma research conducted by the CDC (See Attachment II) revealed that the vast majority of the

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[**] Kitchener, BA and Jorm, AF. Mental Health First Aid: An international programme for early intervention. *Early Intervention in Psychiatry* 2008; **2**; 55-61

[††] Pescosolido, BA, et al. "Cross-Cultural Issues on the Stigma of Mental Illness," Understanding the Stigma of Mental Illness: Theory and Interventions, J. Arboleda-Florez and N. Sartorius, eds. John Wiley & Sons, Ltd 2008 : 19-35

U.S. population agreed that people with a 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 periphery. 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 coalitions 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 experiences and input 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 cannot 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 levels; 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 and 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 health efforts around the nation and when discussing the rebuilding of the mental health system, it is imperative to involve consumers on all levels.

Spotlighted Changes in Stigma

Positive	Negative
• Increase in willingness to discuss mental illness	• Increase in association with violence
• Increase in willingness to seek help	• Permanence implied with genetic

[‡‡] Kobau, R., et al, SAMHSA/CDC Mental Illness Stigma Panel Members. Attitudes about Mental Illness and its Treatment: Validation of a Generic Scale for Public Health Surveillance of Mental Illness Associated Stigma. *Community Mental Health Journal* 2009; DOI 10.1007/s10597-009-9191.

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 for 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 address 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."

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 ten 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 to use, 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 *Illinois 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 presentations 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; doing so would be a way to make stigma and discrimination a national focus and may elicit 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 in dealing with mental health in the community.

3. **Create a resource center to inform effective campaigns/initiatives:**
The group proposed a resource center to provide useful tools and ideas for future anti-stigma initiatives. This information could be a web-based manual where organizations can access evaluation measures, stigma measures, research information, and basic ideas for effective campaigns and initiatives. The SAMHSA-sponsored ADS Center website could provide a home for this kind of resource.

4. **Create a research toolkit:**
The group suggested creating a research toolkit that would provide guidelines for a simple investigation or a simple intervention that could be carried out by persons who are interested in doing research or interventions but who do not have much knowledge nor are instructed in how to do it. The kit would be offered to persons who would collaborate with knowledgeable researchers willing to help with data analysis and who could provide guidance as needed. The goal would be to recruit a younger generation of researchers to focus on stigma and discrimination research.

5. **Communicate priorities within and outside the stigma field:**
The group agreed that some form of publication and/or dissemination of the priorities which had been identified within the meeting should occur. The document(s) circulated should highlight important areas of focus for stigma research and stigma change efforts. The audience should exceed the stigma field and should incorporate the larger health and mental health field.

Due to the Carter Center Mental Health Program's unique ability to convene multiple groups of people within and outside of the mental health field, the Mental Health Program agreed to explore hosting the sixth international stigma meeting in the United States.

The group agreed that the Carter Center Mental Health Program staff should distribute the meeting report to groups outside the mental health community, and not just include the usual mental health community, so as to communicate the meeting deliverables and priorities.

Summary

The one and a half day meeting of international stigma and discrimination leaders and their insightful and informative discussions focused around stigma research and the gaps in the field. Participants reported on current and past studies and identified what stigma research and anti-stigma initiatives need to achieve in the next ten years. The group developed an agenda for next steps, focusing on filling the gaps in research and

improving anti-stigma efforts. The Carter Center Mental Health Program, with support from the National Institute of Mental Health, has been charged with assisting in carrying out the identified deliverables and communicating the outcomes of the meeting to the broader public.

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
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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
Head, "Open the Doors" WPA Global
Program

Heather Stuart, PhD
Professor
Department of Community Health &
Epidemiology

Queen's University

Otto Wahl, PhD
Professor
Graduate Institute of Professional
Psychology
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Federal Government
Rosemarie Kobau, MPH
Public Health Advisor
Arthritis, Epilepsy, and Quality of Life
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Chris Marshall
Consumer Affairs Specialist
Substance Abuse and Mental Health
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Emeline Otey, PhD
Program Chief
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The Carter Center
Thomas H. Bornemann, EdD
Director
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Rebecca G. Palpant, MS
Senior Program Associate
*The Rosalynn Carter Fellowships for
Mental Health Journalism*
The Carter Center Mental Health
Program

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
  - Address prevention and early intervention
  - Train general practitioners; and
  - Incorporate applied research in the field

- Mental Health First Aid Course - Australia

  The Mental Health First Aid Course is a program modeled on first aid training; it provides training in how to give help early to developing mental health problems and how to give assistance in crisis situations. Over 1,000 instructors employed by area health services, non-governmental organizations, and private practices, have trained over 100,000 people. The program is now running in 13 other countries.

- Open the Doors Campaign - World Psychiatric Association

  Open the Doors is a multi-country campaign that convenes international participants and stigma experts to revive interest on the issue of stigma and discrimination towards people living with a mental illness.

- Mental Health Commission of Canada

  Anti-stigma/anti-discrimination initiative is a 10-year project that will begin with a focused effort centering on two groups: youth ages 12-18, and health care professionals.
  - Key to the development of the plan is a coordinated effort between consumers, researchers, and stakeholders.

  Parallel to the initiative, the commission will work to build a research knowledge base that can be utilized by professionals to inform other activities.

  Additional projects include a best practices network that provides evidence-based methods and processes to the field.

Domestic Campaigns
- Campaign for Mental Health Recovery

  In response to the findings from the President's New Freedom Commission in 2003, SAMHSA launched a national anti-stigma campaign that addressed

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, a 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 Centers 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 projects, 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 a mental illness lead normal
  lives

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

Results:
- The vast majority (~88% of those surveyed)* agreed with the first statement, which possibly attests to an increase in informational campaigns on mental illness. Those who were less educated and younger tended to disagree.
- The second statement had much less support across states and across specific conditions. About thirty-five percent of the public disagreed with the second statement, indicating that this is an area that needs improvement.*

For the second study, CDC and SAMHSA assembled a panel to measure stigma with a broader set of questions that could be used on existing surveillance systems—necessitating brevity. The panel modified items from the British Omnibus Survey. A confirmatory validity study (n=5,251) identified 2 general factors: Negative Stereotypes; Recovery and Outcomes.

Results:
- Men had slightly more negative stereotypes; Hispanics and adults of another race/ethnicity had slightly more negative stereotypes than whites or blacks.
- Trends for more negative attitudes toward recovery and outcomes were seen among men and younger adults.*

Definition of Stigma

- Stigma Measures and Domains
  In Dr. Corrigan's work, he identified five different types of stigma and the corresponding strategies for stigma change:
    1. Public stigma- the general population endorses the prejudice and discrimination of mental illness *(Strategies for change: protest, education, and contact)*
    2. Self-stigma- awareness, agreement, and self-application of stereotypes *(Strategies for change: encouraging individuals to publicly identify themselves as consumers and supporting consumer empowerment)*
    3. Label avoidance- people do not seek services, or drop out of those services prematurely, in order to escape the stigmatizing mark of mental illness *(Strategies for change: protest, education, and contact)*
    4. Institutional/Structural- policies or systems are discriminatory towards individuals with mental illnesses *(Strategies for change: affirmative action; examination and change of policies)*

5. Courtesy stigma- the stigma that befalls associates of people with mental illness *(Strategies for change: encouraging individuals to publicly identify themselves as consumers and creating consumer empowerment)*

Five measurement domains for measuring stigma within a population:
6. Penetration- recognition and/or recollection of medium and message (*i.e.* PSAs)
7. Psychological perspectives- attitudes and stereotypes, emotions, and behavior intentions
8. Knowledge and mental health literacy- knowledge about disease/disability and treatment
9. Physiological and information processes- how physiological responses and implicit and explicit processes may explain stigma and how stigma change can improve people's recognition
10. Promotion of positive behaviors- shifting focus from discriminating behaviors to positive behaviors such as support, opportunity, and service participation

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 6th 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 and 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