



BEYOND STIGMA

Advancing the Social Inclusion of People with Mental Illnesses

Summary of the 28th Annual Rosalynn Carter Symposium on Mental Health Policy

In November 2012, Rosalynn Carter, co-founder of The Carter Center and former U.S. first lady, brought together more than 200 people from the mental health community to discuss ways to build social inclusion for people living with mental illnesses. This summary highlights the major themes of the 28th Annual Rosalynn Carter Symposium on Mental Health Policy, held Nov.1–2, 2012, in Atlanta, Ga.

n the nearly three decades since The Carter Center offered its first Rosalynn Carter Symposium, much has changed in the world of mental health, both for individuals struggling with mental health conditions and for their caregivers and providers. The voices on stage in 2012 reflected a diversity of stakeholders—psychiatrists, counselors, professors, lawyers, artists, clergy, administrators, journalists, and CEOs—not seen in the early days of the symposium. In addition, many participants were able to speak from experience, bringing a practical and personal perspective new to the mental health policy field.

The consumer voice, especially, is more relevant than ever before as many of the organizations and networks that provide health care, housing, and other support services increasingly are staffed and even led by mental health consumers, whose knowledge of these illnesses offers invaluable insight into the lives of those they are trying to help.

But despite the progress that has been made, cultural stigma continues to oppress people living with mental illnesses even when they are successfully managing their symptoms. Stigma still

forces those with mental illnesses into wrenching dilemmas: suffer in silence or risk potential ostracism from family and friends. In fact, self-stigma, a person's embarrassment or shame at having a mental illness, often instills an even more powerful fear of his or her condition, stifling hope and ambition, limiting their dreams.

Defining Stigma

What is stigma? What causes it? Multiple

Stigma is the belief in a fundamental difference between those with mental illnesses and others. This belief, both consciously and unconsciously, results in those with mental illnesses being denied certain aspects, services, and roles of modern life.



Rosalynn Carter, head of the Carter Center's Mental Health Task Force, welcomes participants to a November 2012 symposium on fighting the stigma against people with mental illnesses.

definitions and descriptions found their way into the Rosalynn Carter Mental Health Policy Symposium, although most could be boiled down to a simple idea: Stigma is the belief in a fundamental difference between those with mental illnesses and others. This belief, both consciously and unconsciously, results in those with mental illnesses being denied certain aspects, services, and roles of modern life.

Symposium keynote speaker Graham Thornicroft, Ph.D., summarized the causes and manifestations of stigma by naming three related problems that can be used to break down a vast, shape-shifting idea into approachable issues: problems of knowledge, emotion, and behavior. These are the components upon which many anti-stigma campaigns are constructed.

Media Can Provide the Power of Knowledge

"The problem [regarding people's perceptions of mental illness] is that they have availability of very poor misinformation," Thornicroft said. "They don't know how common mental illnesses are. They don't know how much we can treat them." Contributing to slow but steady progress against stigma is a distinct shift in how mental illnesses are portrayed in the popular media.

In a presentation during the symposium, actress Glenn Close,

Faige Kohe

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who, along with her sister, Jessie Close, founded the anti-stigma campaign Bring Change 2 Mind, pointed specifically to the cable television series "Homeland," in which the main character works

for the CIA while managing a challenging mental illness.

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Personal Relationships Bring Emotional Connections

For fighting myths and misperceptions about mental illness, personal relationships are powerful tools. People without mental illnesses gain firsthand knowledge about these conditions from relatives,

colleagues, or friends. While acknowledging the tremendous difficulty in "coming out" with a mental illness, speaker after speaker at the symposium described the equally tremendous positive impact it can have. Coming out as a mental health consumer has risks: people fear estrangement from friends and family and loss of health coverage, employment, or even their homes. But those with personal experience who took the symposium stage urged others to take that very public step to help both themselves and the entire mental health community.

Full Participation in Society

Standing in opposition to stigma is the concept of social inclusion, a full opportunity to participate in society. Australian Monsignor David Cappo, speaking at the symposium, said social inclusion was "about increasing participation in economic and social life; access to services, learning skills, jobs; and very much about giving people a voice. A voice is about recognition, and perhaps this is the key expression to enhancing the human dignity of people who are on the edges of our society."

Toward Recovery

Speaker Paolo del Vecchio, director of the U.S. Substance Abuse and Mental Health Services Administration's Center for Mental Health Services, said he envisioned that the foundation for social inclusiveness would include health, home, purpose, and community.

He noted that, ultimately, social inclusion is not just about giving mental health consumers access to mainstream services; it

- "By any measure, it's clear we are on the margin. In fact, too many of us are not on the page at all. We're the poorest of the poor: unemployed, uneducated, and ill-housed. We're unhealthy, victimized, and socially isolated, dying decades earlier than the general population."
 - Paolo del Vecchio, director of the Center for Mental Health Services, Substance Abuse and Mental Health Services Administration, and panelist

"Coming out as a person with severe mental illness carried substantial professional and personal risk [for me]. And it will remain that way until people feel safe coming out and telling their stories. If you hear nothing else today, please hear this: There are no schizophrenics. There are people with schizophrenia, and these people may be your friends, your neighbors, your family members, and your workmates."

Elyn Saks, Orrin B. Evans Professor of Law,
University of Southern California, and keynote speaker

is about making sure they have the support, encouragement, and incentive to actually participate. And like many of his fellow speakers, del Vecchio was living proof that once consumers are given that chance to fully participate, many of them will take advantage and become productive, successful members of society.

"I'm reminded of the words of Arthur Ashe when he challenged so many of us to do more in our communities," speaker Sandra Underwood said. "He said, 'Start where you are, use what you have, and do what you can to effect change.' Using what we have to effect change is what we need to do. We need to do it today."

For more information on the Rosalynn Carter Symposium on Mental Health Policy, please visit www.cartercenter.org.

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