

Beyond Stigma

ADVANCING THE
SOCIAL INCLUSION
OF PEOPLE WITH
MENTAL ILLNESSES

REPORT OF THE
28TH ANNUAL
ROSALYNN CARTER
SYMPOSIUM ON
MENTAL HEALTH
POLICY

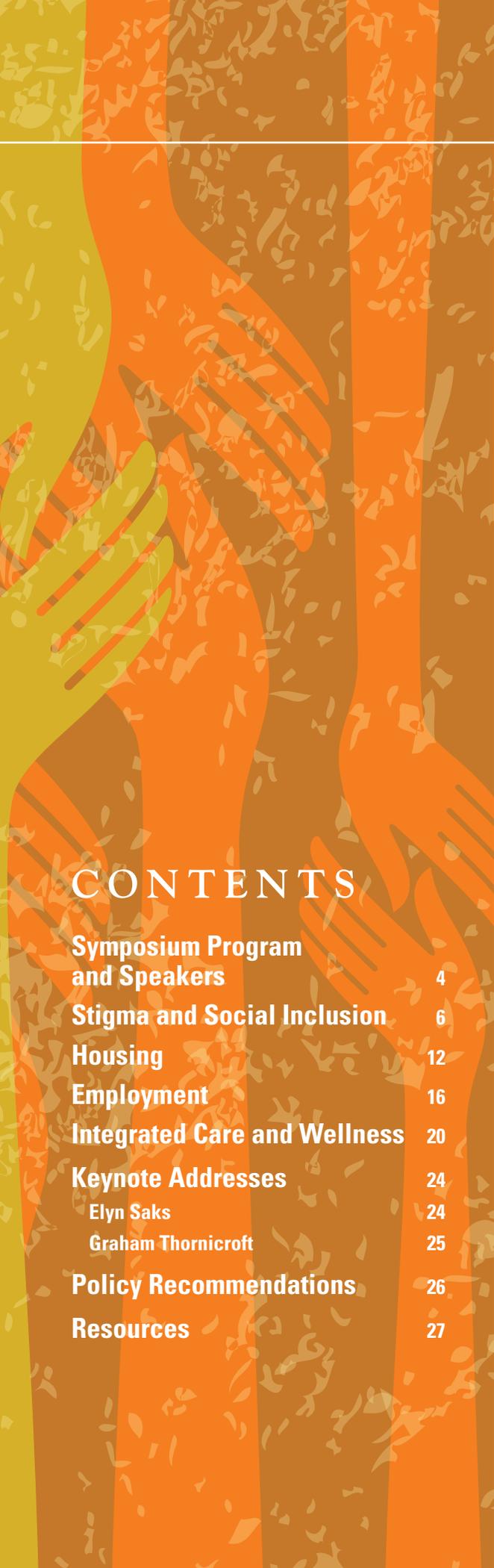
NOVEMBER 1 & 2,
2012

THE
CARTER CENTER



INTRODUCTION





“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

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In the three decades since The Carter Center offered its first Rosalynn Carter Symposium on Mental Health Policy, much has changed in the world of mental health—both for individuals struggling with mental health conditions and for their caregivers and providers. Unlike the psychiatrist-dominated agenda of that first symposium, the voices on stage in 2012 belonged to professors, mental health consumers, lawyers, artists, clergy, administrators, journalists, CEOs, counselors (even a psychiatrist or two)—many of whom spoke from their own lived experience.

Several speakers noted that there is now a vocabulary to talk about mental health. Popular portrayals of mental illness in film and television have become more fully dimensional, showing complex characters who integrate their conditions into the “normal” chaos of life. Perhaps most importantly, 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 — individuals whose own battles with illness have left them with invaluable insight into the lives of those they're trying to help.

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But, despite all the progress that's been made, cultural stigma remains the (usually) invisible shackle that oppresses those living with mental illnesses even when they're successfully managing their own symptoms. Stigma still prevents people from speaking honestly with family and friends. It still forces those with mental illness into wrenching dilemmas (like whether getting a job is worth the risk of losing Social Security disability benefits). Stigma still haunts the darker regions of too many minds, even those of doctors and nurses in hospitals and clinics all over the country and the world. In fact, self-stigma all too often instills fear in those with mental illnesses, stifling hope and ambition, forcing a ceiling upon their dreams.

Unfortunately, smothered dreams are not the most severe consequences they face. Speaker after speaker at the 2012 symposium pointed to the 25-year gap in life expectancy between those with serious mental illnesses served by the public mental health system and the rest of the population, according to the landmark 2006 report, "Morbidity and Mortality in People

with Serious Mental Illness." This disparity, keynote speaker Graham Thornicroft said, stretches across cultures, across health care systems, across ideologies, across rich nations and poor.

"By any measure, it's clear we are on the margin — in fact, too many of us are not on the page at all," said Paolo del Vecchio of the Substance Abuse and Mental Health Services Administration (SAMHSA). "We rank at the bottom of every major social indicator. 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."

And, yet, infused in the stories of every speaker was a sense of hope. Whether it was through personal testimonies of overcoming illness and stigma, data-filled reports of successful programs in supported housing or employment, or emotional accounts of changing perceptions one mind at a time, the speakers who took the Carter Center stage for two days in early November 2012 all shared messages of progress — of never giving up.

This report of the 2012 Rosalynn Carter Symposium on Mental Health Policy is organized along similar lines to the symposium itself but not bound by them. Its sections are delineated by the same topics—stigma and social inclusion, housing, employment, and integrated care and wellness—but each section pulls relevant ideas and statements from the event’s entirety rather than solely from its associated panel discussion. Both keynote addresses are summarized, and recommendations from the symposium’s working groups are called out in detail. Finally, the end of the report features a comprehensive list of the many resources—organizations, programs, websites, studies, books, and so forth—shared over the symposium’s one-and-a-half days.

“Stigma has lifted a little bit,” Mrs. Carter said in her concluding remarks to the event. “Now that we have more information about how to go about changing the stigma, and with so many people here from all parts of the country, I just feel confident that we can do something about it—in my lifetime.”



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.

Rosalynn Carter’s Role with Mental Health Issues

Rosalynn Carter has been a visible, active leader in the mental health field for over 40 years. During the Carter presidential administration, she served as honorary chair of the President’s Commission on Mental Health from 1977–1978. Upon returning to Georgia in 1981, Mrs. Carter collaborated with the Emory University Department of Psychiatry to pursue her ongoing interest in mental health. In 1985, they organized the Rosalynn Carter Symposium on Mental Health Policy. Each year, this event brings together national leaders in the mental health community to examine an issue of common concern.

With the inception of the Rosalynn Carter Fellowships for Mental Health Journalism in 1996, Mrs. Carter launched one of the most successful national programs to address the stigma associated with mental illnesses. Mrs. Carter also has been the driving force behind the Carter Center Mental Health Task Force, which provides continuity between the annual symposia and guides the activities of the Mental Health Program staff.

SYMPOSIUM PROGRAM AND SPEAKERS

THURSDAY, NOVEMBER 1, 2012

WELCOME

Thomas Bornemann, EdD, Director, The Carter Center Mental Health Program

OPENING REMARKS

Rosalynn Carter, Chair, Carter Center Mental Health Task Force

KEYNOTE I

Elyn Saks, PhD, JD, Orrin B. Evans Professor of Law, Psychology, and Psychiatry and the Behavioral Sciences, University of Southern California Gould Law School

CONVERSATION: TRANSFORMATIONAL CHANGE

Moderator: Joanne Silberner, Artist-in-Residence, Department of Communication, University of Washington; Rosalynn Carter Fellow for Mental Health Journalism 2009–2010

Gay Community: Asaf Orr, JD, Staff Attorney, National Center for Lesbian Rights

Civil Rights: Dr. C.T. Vivian, President, Southern Christian Leadership Conference; Founder, C.T. Vivian Leadership Institute

Breast Cancer: Sandra Millon Underwood, RN, PhD, FAAN, American Cancer Society Oncology Nursing Professor, University of Wisconsin-Milwaukee

HOUSING PANEL

Moderator: Kim Horner, Communications Director, Metro Dallas Homeless Alliance; Rosalynn Carter Fellow for Mental Health Journalism 2008–2009

Panelists: Monsignor David Cappelletti, Archbishop's Office, Adelaide; Australia Social Policy and Reform Advocate

Michael W. Brose, MS, Executive Director, Mental Health Association in Tulsa

Kimberly Cummings, Executive Assistant, Mental Health Association in Tulsa

FRIDAY, NOVEMBER 2, 2012

KEYNOTE II

Graham Thornicroft, PhD, Professor of Community Psychiatry, Head of Health Service and Population Research Department, Institute of Psychiatry, King's College London

EMPLOYMENT PANEL

Moderator: **Andy Miller**, CEO/Editor, Georgia Health News

Panelists: **David Lynde, MSW**, Mental Health Consultant

Margaret (Peggy) Swarbrick, PhD, OT, CPRP, FAOTA, Director of the Collaborative Support Programs of New Jersey Institute for Wellness and Recovery Initiatives

Gretchen Grappone, LICSW, Clinician and Trainer, Mental Health Center of Greater Manchester, New Hampshire

INTEGRATED CARE AND WELLNESS PANEL

Moderator: **Michelle Roberts, MS**, Director of Communications, Health Literacy Missouri; Rosalynn Carter Fellow for Mental Health Journalism 2004–2005

Panelists: **Paolo del Vecchio, MSW**, Director, Center for Mental Health Services, SAMHSA

Joseph Parks, MD, Chief Clinical Officer, Missouri Department of Mental Health

Daniel Fisher, MD, PhD, Executive Director, National Empowerment Center

SPECIAL PRESENTATION

Public Release of the CDC report “Attitudes Toward Mental Illness: Results From the Behavioral Risk Factor Surveillance System” (BRFSS)

Robin M. Ikeda, MD, MPH, Director, Office of Noncommunicable Diseases, Injury, and Environmental Health, U.S. Centers for Disease Control and Prevention

Paolo del Vecchio, MSW, Director, Center for Mental Health Services, SAMHSA

TOWN HALL MEETING

FACILITATORS: **David Shern, PhD**, Past President, Mental Health America

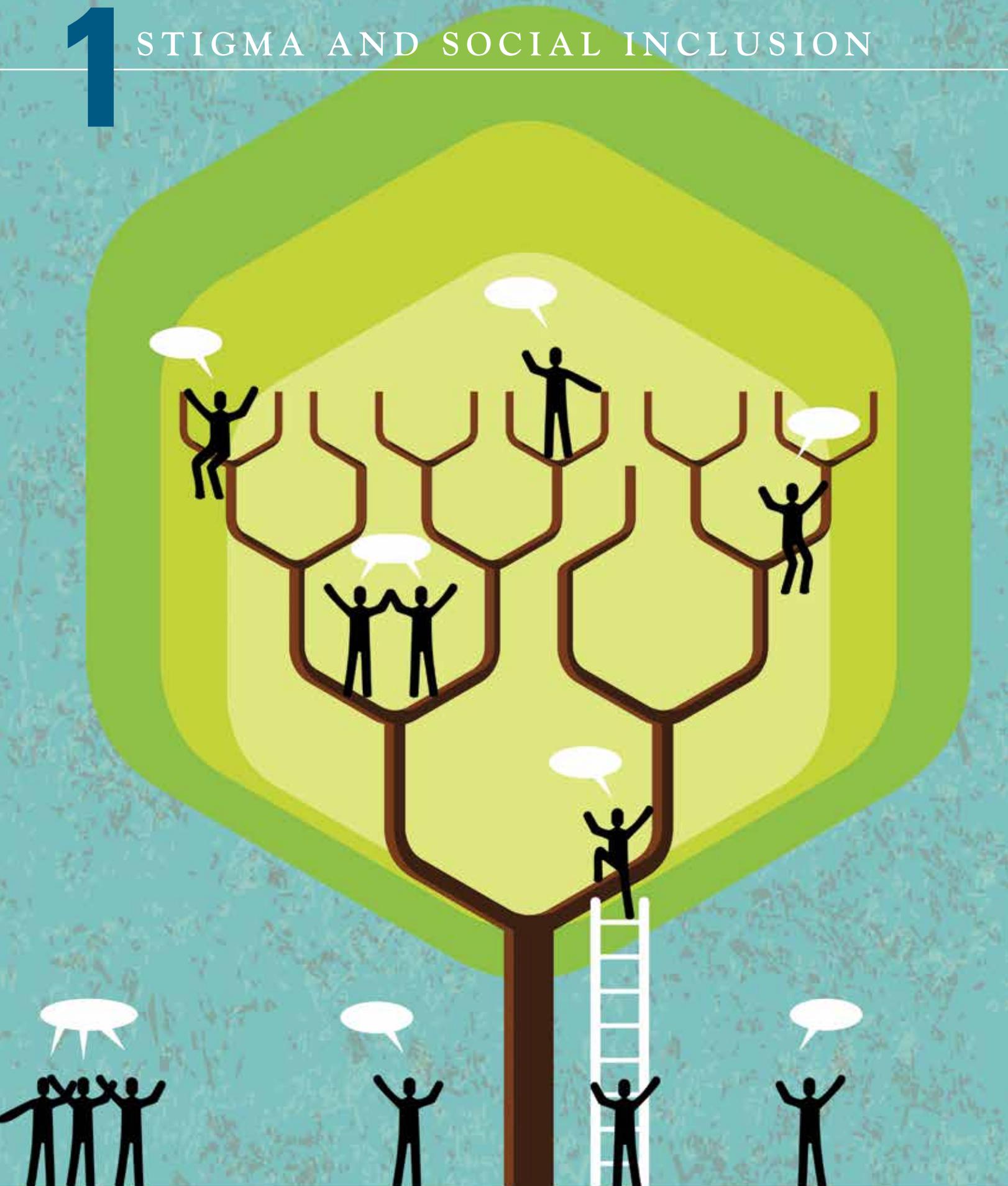
Bernice Pescosolido, PhD, Distinguished and Chancellor's Professor of Sociology, Indiana University; Director of Indiana Consortium for Mental Health Services

CONCLUDING REMARKS

Rosalynn Carter, Chair, Carter Center Mental Health Task Force

1

STIGMA AND SOCIAL INCLUSION



“I am because you are, and you are because we are.”

—Panelist Paolo del Vecchio, quoting an African Ubuntu proverb

A large, stylized letter 'W' graphic composed of many small, dark blue dots, positioned at the start of the first paragraph.

What is stigma? What causes it? How does it manifest in thought and action, not only those of the stigmatizing agent but of the stigmatized as well? Multiple definitions and descriptions found their way into the 28th symposium, though most could be boiled down to a simple idea: Stigma is the belief in a fundamental difference between those with mental illness and others. This belief, both consciously and unconsciously, results in a denial to those with a mental illness of certain aspects, services, and roles of modern life.

“When we battle our own internal demons of stigma, it’s easier to say, ‘I can do this. You can’t. It’s what makes me different from you,’” said mental health consultant David Lynde. “But when we start to say, ‘I can do this, and you can do this,’ then we start to change our whole view of who is ill and who is not. We start to move toward a spectrum of health and wellness.”

As for causes and manifestations, keynoter Graham Thornicroft covered both in identifying three related problems that he said help break down a vast, shape-shifting idea into approachable issues: knowledge, emotion, and behavior. Indeed, lack of knowledge of mental health issues repeatedly was held out as the predominant cause of stigma, and one that leads directly to Thornicroft’s second problem, emotion — namely fear.

Fear, the symposium revealed, drives stigma across large swaths of the human condition. Civil rights pioneer C.T. Vivian spoke of the fear that’s “basic in all of us” and how it continues to stoke the fires of racism, despite the past half-century’s progress. Professor and oncology nurse Sandra Underwood recalled the fear, the “sense of fatalism,” that lay underneath the stigmatizing of breast-cancer patients in the 1970s. Mental health administrator and therapist Margaret Swarbrick singled out fear as the biggest challenge to mental health consumers themselves — fear of their symptoms, fear of discovery, fear of failing to hold a job or keep a home.

But fear is fixable. Ignorance can be dispelled. For evidence, Underwood said, look no further than the “phenomenal strides” made in breast-cancer awareness after nearly 30 years of public campaigns, three-day walks, and pink ribbons. Panel moderator and former Rosalynn Carter journalism fellow

Joanne Silberner recalled how, in telling one of her University of Washington students about the symposium, she described how cancer patients were stigmatized when she was young. The student didn't believe her.

The Power of Knowledge— Through Media

“The problem [regarding people's perceptions of mental illness] is that they have availability of very poor information,” Thornicroft said. “They don't know how common mental illnesses are. They don't know how much we can treat them. They don't know how [many] people in the community all around us do have mental health conditions.”

In 2007 the two leading mental health charities in England, Mind and Rethink Mental Illness, launched an awareness campaign to confront ignorance of mental health issues head on. Part of the campaign was a series of short films and public service announcements showing not only mental health consumers as active participants in “normal life,” but also their friends and colleagues—people dealing with their own lack of knowledge yet finding a way to interact with those close to them who were coping with mental illness.

“The call to action is talk, talk, talk, talk,” said Thornicroft, who showed several clips of those films to the symposium audience. Since the campaign began, he said, his country has seen a wide range of modestly positive outcomes in survey measurements of mental health stigma and discrimination. Awareness campaigns in other European countries as well as Canada and the United States also have been shown to yield measurable results, though Thornicroft said the evidence so far is limited to high-income nations.

No doubt contributing to slow but steady progress against stigma is a distinct shift in how mental illness is portrayed in the popular media. Actress Glenn

Close, who founded the U.S. awareness campaign Bring Change 2 Mind, pointed specifically to the cable television series “Homeland,” with its character Claire Matheson (played by Claire Danes) integrating her life in the CIA with a challenging mental illness. Another example is the protagonist of the hit 2012 film “Silver Linings Playbook,” a schoolteacher (played by Bradley Cooper) who tries to rebuild his life after spending time in a mental health facility. Of course, this shift is true of many—but not all—Hollywood projects.

“I have turned down just recently at least three scripts because I thought they were irresponsible writing about mentally unstable people,” Close said. “I just don't want to have anything to do with perpetuating that kind of stigma, that kind of misunderstanding. There must be ways to portray mental illness in [more positive] ways. “Homeland” is a perfect example. It's an incredible plot and a very compelling [character], who just happens to be bipolar.”

No less critical are the informed cooperation and support of media at a local level. Multiple symposium speakers hammered at the importance of reaching out to local news outlets and working with them to tell positive stories of people living with mental illness in the community. After all, Lynde said, the closer these stories are to the people who need to hear them, the more effective they will be.

Keynoter Elyn Saks agreed. “When the public sees people with mental illness thriving in their community, that dispels stereotypes and lessens stigma,” she said. “That in turn opens more doors and creates more opportunities. That's the road we should be traveling.”

Making It Personal

Of course, when it comes to battling the demons of ignorance, nothing compares to personal knowledge of and relationships with people with mental illness.

Personal contact with mental health consumers was far and away the most frequently cited key to breaking down stigma. Speaker after speaker, while acknowledging the tremendous difficulty in “coming out” with a mental illness, described the equally tremendous impact it can have.

“Part of it is humanizing [the individual] and part of it is the visibility—that folks [realize they] know other people who are living with mental illness, that it’s just part of the things they manage every day,” said attorney Asaf Orr, in sharing the hard-won lessons of the LGBT (lesbian, gay, bisexual, transgender) community in overcoming much of its own stigma. “Once you have that visibility, you’re going to get more folks who are willing to see [mental illness] as part of the broader human spectrum.”

Coming out as a mental health consumer has risks—people fear estrangement from friends and family, loss of health coverage or employment, even loss of their homes. But those with lived experience who took the symposium stage urged others like them to take that very public step to help both themselves and the entire mental health community.

“Consider talking openly about your experience, especially if you’re in the field of mental health,” urged mental health clinician and trainer Gretchen Grappone. “I’ve been speaking openly for many years about my experience with depression, and I can honestly say 99.9 percent of the time I have extremely positive reactions. In fact, my decision to speak about my depression has, perhaps more than anything else, decreased my social isolation.”

“Every time I talk about my mental illness, I experience—and it’s getting smaller but I do still experience—a teeny-weeny little bit of self-stigma,” said Jessie Close, Glenn’s sister and partner in Bring Change 2 Mind.

Jessie’s decision to speak publicly about her experience led to her appearing in the organization’s first public service announcement, directed by Ron Howard, the famous Hollywood director. She recalled standing in New York’s Grand Central Station wearing a T-shirt that read, “Bipolar.” Next to her was her then-21-year-old son, wearing a shirt that said, “Schizophrenia.”

“That was really scary,” Jessie said. “It’s one thing having family and friends know [about your mental illness]. It’s another thing to be standing with hundreds of people.”

And afterward, how did she feel? “It was glorious,” Jessie said.

We’re All Those People

Standing in opposition to stigma is the prospect of social inclusion: full opportunity to participate in society. Just as with stigma, symposium speakers brought their own specific definitions of social inclusion. Much like England’s Thornicroft broke down stigma into three addressable problems, Australian Monsignor David Cappo approached social inclusion from four directions: barriers, participation, access, and voice.

“Those barriers can be personal ones, often related to access to services or particular systems’ barriers,” Cappo said. “It’s about increasing participation in economic and social life; access to services, learning skills [and] 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.”

Cappo spoke from 10 years of experience with an Australian program targeted at social inclusion and focusing on housing populations with high rates of mental illness, including ex-prisoners and the homeless. Talking more from her own lived experience—and

with a matter-of-fact candor that brought her a standing ovation from the symposium audience—was Kimberly Cummings, an executive assistant from Tulsa, Okla. After first trying alcohol at age 14 and methamphetamines two years later, Cummings spent some 23 years in “active addiction,” she said, culminating in a 2009 felony conviction.

But Cummings turned her life around—and avoided prison. She was offered a chance to participate in a pilot program for female offenders like herself, where she would live in transitional housing and enter a full-time, outpatient treatment program. Soon she began working again, and in December 2009 she moved into her own apartment and was reunited with her children.

Now Cummings is a walking definition of social inclusion. She works for Tulsa’s Mental Health Association, supporting its executive director. She is “a loving mother of three children—who actually have the mother they’ve always deserved to have.” She’s enrolled in classes and working toward becoming a drug and alcohol counselor. She’s spoken to both houses of Oklahoma’s legislature about the effectiveness of alternatives to incarceration. And she gives back to the same program that helped her, mentoring women who are struggling to make the same changes she did.

“I do advocate for those people,” Cummings said. “I am those people. We’re all those people, on some level.”

Toward Recovery

According to Benjamin Druss, Rosalynn Carter Chair in Mental Health in Emory University’s Rollins School of Public Health, Cummings’ story is doubly instructive. As the mental health community searches for a proper meaning of “recovery” for individuals with mental illness, Druss pointed to the definition used regarding substance abuse. In fact, he called it “central.”

“It’s all about getting past thinking of yourself as being a diagnosis, of having a diagnosis,” Druss said. “It’s about living your life, about focusing on strengths and opportunities.”

The Substance Abuse and Mental Health Services Administration (SAMHSA) has identified four “pillars” to support people on their journeys toward recovery, SAMHSA Director Paolo del Vecchio said: health, home, purpose, and community. “We see these,” del Vecchio said, “as the building blocks of a socially inclusive community.”

In the end, he added, social inclusion is not just about giving mental health consumers access to mainstream service—it’s 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 full advantage and become full-fledged, productive members of society.

“Until recently, many didn’t think recovery was possible,” del Vecchio said. “Some still don’t today. The concept of recovery has emerged through our lived experience.”

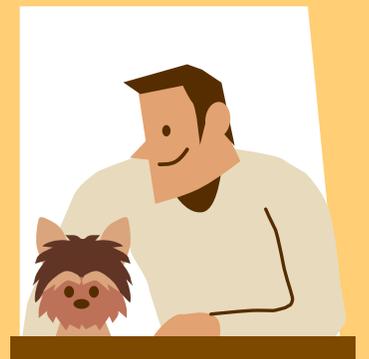
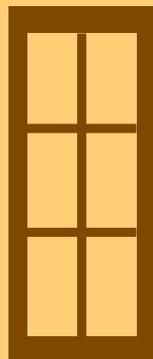
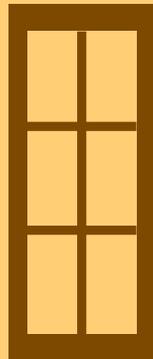
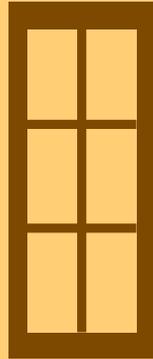
But what about the recovery of a society? What kind of therapy will help a culture move past its prejudice? How many steps will it take the world to kick the habit of stigma—and where does the path begin?

It begins, many speakers maintained, in the communities that surround us all: making those small, vital local connections between service providers, empowering and encouraging mental health consumers to talk openly about their experiences, and even equipping them with the knowledge and tools they need to mentor and serve as examples to their peers. For many people dealing with mental illness—but not all—it can even start with something as simple as a friend offering help, or a family member who gives a loving reminder that depression need not be battled alone.

“When I’m feeling unwell,” Saks said, “it’s helped me when my friends say, ‘Elyn, it looks like you’re slipping. You seem really scared. It’s your illness acting up, and we’re going to get it under control.’ That really helps me.”

“I’m reminded of the words of Arthur Ashe when he challenged so many of us to do more in our communities,” Underwood said. “Arthur Ashe 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.”

2 HOUSING



“The most foundational, powerful thing that having that one-bedroom apartment did was allow me to begin to [reunite] with my three children.... I felt a sense of empowerment that was — it’s sometimes very hard to explain — that this was a home of my own, that this was a home of our own, that we could actually begin our lives now. I started to feel good. I started to feel like a human being again.”

—*Kimberly Cummings, Executive Assistant, Mental Health Association of Tulsa*

If recovery is a path, then symposium speakers set down stable housing as perhaps the first, most important flagstone. Around it can be placed the employment, health care, and social support services that help keep mental health consumers headed forward on the path. Housing also promises escape from one of society’s most oppressive stigmas — that against the homeless. As panel moderator Kim Horner said, the image of the urban homeless has become so commonplace that it’s lost its ability to shock. Indeed most Americans experience fear and animosity toward the homeless, though one in five served his or her country in the military.

Australia has been successful in combating homelessness with a wide approach, first taking an expansive survey of the problem itself and then of government resources that could be brought to bear. “Joined-up solutions,” Monsignor David Cappelletti called the 10-year effort by the state of South Australia. As an independent commissioner, Cappelletti directed 20 state employees spread throughout the government and charged with coordinating multiagency efforts to meet a clear goal: Cut the number of homeless in half within eight years.

“[In six years] we’d achieved the target in the city,” Cappelletti said. “How did we go about it? Firstly, see [homelessness] as a system. Map the homeless system and overlay where the resources are placed and see the gaps. See where the entrance points and the exit points are in a system. See where people are getting caught within the system.”

Examples of such entryways and stopping points are the justice system and homeless shelters. Too few people completing terms of incarceration get the help they need to transition back into society, and too many chronically homeless come to view shelters as an end- rather than a checkpoint.

“Shelters were never created for people to live in,” said mental health administrator Michael Brose. “That’s what they’ve become in America. They were never intended for that. They’re short term [and] we’ve got to have them return to their right role. That means we’ve got to create a lot more affordable housing that [people] can access.”

One Oklahoma city has done just that. Brose’s Mental Health Association of Tulsa has overseen the acquisition of millions of dollars in residential units that were then converted to affordable, quality housing for people in the mental health, addiction, and correctional systems. Emblazoned across the buildings pictured on bright sunny days in Brose’s slides were such names as the Altamont, South Wind, Tree Point, Bell Arms, Ranch Acres, Brighton Park — appellations of normalcy that most Americans take for granted but that can represent so much to a mental health consumer struggling to maintain a sense of self-ownership.

Brose’s assistant Kimberly Cummings — who once lived in one of the very buildings in Brose’s slides, after having overcome years of addiction and depression — was a vivid example of how housing helps people begin to reassemble their lives. Horner cited another in Texas, where hundreds of units of supported, affordable housing have helped the city of Dallas reduce its homeless population by two-thirds since 2004. And administrator Peggy Swarbrick provided another in the 500 mental health consumers who today are living in peer-run housing around the state of New Jersey.

Fighting Stigma Through Education and Policy

Unfortunately stigma not only casts a net of prejudice over the homeless, it also actively resists efforts to help people get off the streets. The need to overcome neighborhood resistance to affordable housing for mental health consumers was a common obstacle cited by multiple speakers. In New Jersey, in Tulsa, even in keynoter Graham Thornicroft’s experiences in London, housing programs became bogged down by the all-too-human tendency toward nimbyism. Horner said several projects in Dallas had withered and died in the face of opposition.

However, most of the stories ended positively, with consumer efforts at education and negotiation finally lowering the stigma barrier at least enough to allow progress. Brose talked of pulling up to the local Tulsa newspaper in a van and taking the entire editorial board for a tour of his agency’s work — and doing the same with city business leaders and other potential donors to its \$30 million capital campaign, which in November 2012 was just \$1.5 million from completion.

Of course, favorable policy can be quite an effective lever to overturn stigma as well. Together with a campaign of public education and good will, Brose took advantage of nondiscriminatory provisions in the 1988 Fair Housing Amendments Act to pursue certain projects while attempting to avoid any public hearings. Swarbrick described a similar strategy in New Jersey. It is perhaps both inspirational and unfortunate that such an approach did help achieve success in both cases.

“We did supportive housing [in New Jersey], went into communities and didn’t tell them we were coming,

because we [informed neighbors] the first time we were coming and everybody blocked us,” Swarbrick said. “[Sometimes] you need to go in. We could get that housing because we deserved it just like anybody else.”

Funding is another area where policy is critical. Multiple speakers cited the U.S. Department of Housing and Urban Development’s Section 811 as vital in obtaining federal grants to help jump-start projects. While limited, federal funding was an important thread in Brose’s work to braid together a net of public and private support that allows the Mental Health Association of Tulsa to own its properties debt-free, which in turn helps keep rent affordable for its low-income residents.

Success and support in red-state Oklahoma have been so encouraging that Brose also helped lead an effort to address provision of the next step to recovery—placing and integrating necessary services around all the safe, affordable, decent housing his agency had provided. Sixteen different public, private, and faith-based organizations have coalesced behind A Way Home for Tulsa, a comprehensive effort to end chronic homelessness in the city by 2015.

“Most of the money I’ve raised for our housing has come from very conservative [donors], because nobody likes homelessness, I don’t care if you’re red or blue or green,” Brose said. “If I’ve learned anything from the tours we’ve given, it’s [that this reaction] is almost universal: They say, ‘I had no idea. I did not understand this. I come to your gala every year and have written you checks, but I really didn’t understand what you were talking about. Now I do.’”

“That’s the message,” Brose said, “that we’ve got to get out into the wider public.”

3 EMPLOYMENT



“Work is the key to my wellness and recovery. I really want to share that. I want to share that there’s hope that people who live with whatever we call a mental disorder ... can achieve personal goals and dreams, and become contributing members of society. And it’s done through employment.”

—Margaret “Peggy” Swarbrick, Director of Collaborative Support Programs,
New Jersey Institute for Wellness and Recovery Initiatives

W

hen Peggy Swarbrick was a young woman, after she’d spent time as an even younger woman in a mental health facility, she decided to go back to school. She wanted to be a nurse. She wanted to effect change in the system she’d witnessed firsthand, and for Swarbrick the path to change led through nursing school. Her mother was not supportive.

“They’re going to find out about you. Don’t go for that degree,” Swarbrick recalled her mother telling her. “Well, what do you do when your mother tells you ‘no’? You do it anyway.”

So Swarbrick found a program, and she enrolled, and soon she landed an internship, and one day during her internship she told her colleagues that, yes, she was quite familiar with the psychiatric setting because she had spent time in it as a patient. And then Peggy Swarbrick lost her internship. Officials at her school asked her to leave the program. Her mother had been right.

“I said, ‘Wow,’” she said.

Unfortunately Swarbrick’s story is familiar to anyone working in mental health. Symposium keynoter Elyn Saks had one just like it, as did other speakers. Too often the stigma facing mental health consumers in their personal lives is reflected, even intensified, in the job world. Employers have—or are perceived to have—biases against mental illness that prevent them from hiring those who they know have suffered from it. And even when a hiring official is not so prejudiced, many times the consumers themselves are all too ready to supply the self-stigma that haunts their own minds: You can’t do this. They’ll find out. You will fail.

But Swarbrick’s story did not end with failure, nor did Saks’. They persevered, and each succeeded, quite possibly beyond the limits of her own beliefs. Indeed, both women credit the pursuit of successful careers as key to their

own recoveries—the sense of achievement, of self-worth and purpose, provided a therapy no medication or support group could match.

“Using my mind,” Saks said, “is one of the most potent weapons against my mental illness. As I’ve come to say, my mind is both my worst enemy and my best friend.”

Set Up for Success

Stigma in the workplace is all too real and perhaps more understandable than social stigma. With money and livelihoods on the line, it’s no wonder that employers tend to make the “safe” choice and avoid hiring employees with known mental illness. According to consultant David Lynde, the employment rate for those receiving services for severe mental illnesses averages somewhere between 5 and 15 percent. Even mental health practitioners and caregivers too often discourage consumers from pursuing meaningful, challenging work.

“When people have other physical injuries, I don’t hear [their support system] saying, ‘Don’t set your expectations too high,’” Lynde said. “I don’t hear, ‘Don’t set them up for failure.’ I hear people saying, ‘Good for them.’ But when somebody has schizophrenia, or somebody suffers from bipolar disorder, and they say, ‘I want to be a lawyer, I want to be a doctor, I want to be an astronaut,’ I hear a chorus of people saying they need to acknowledge they have an illness and to acknowledge their limitations.

“Let’s not set people up for failure,” he said. “Let’s set people up for success.”

Supported Employment

The key is not to simply throw individuals into the working world with no direction or help. Evidence abounds for the success of supported employment programs in helping mental health consumers transition successfully into the job world. Working with other care services, with employers, and with individuals themselves, these programs help guide consumers toward the right jobs for their wants and needs, then maintain engagement through an integrated care model that views employment as another aspect of recovery to be managed.

Sharing his experience of 12 years co-directing the Dartmouth Evidence-Based Practices Center at the Dartmouth Psychiatric Research Center, Lynde stressed the importance of grounding this approach widely in the community. Not only should counselors talk with—and, more importantly, listen to—mental health consumers regarding their goals, but supported employment programs need to go far beyond simply searching the job boards for open positions.

“Employment specialists in this model don’t sit in an office looking online,” Lynde said. “It’s not a model that goes out to employers and says, ‘We’d like you to hire somebody with mental illness because they need a break.’ It’s a model that goes out to employers and says, ‘We want to understand what you need, and we want to match you with somebody who has the skills, ambitions, qualities, strengths, and motivations that you need in your workplace.’”

Employment and Mental ‘Health’

Another way to set mental health consumers up for successful employment, Lynde continued, is to dismiss common misperceptions, like the belief that work is too stressful for those with mental illness. After all, he said, is the stress of a job greater than the stress of an involuntary hospitalization, or of homelessness, or addiction?

“After spending a lot of time working with people with mental illness,” Lynde said, “I began to realize something: They knew something about managing stress.”

Another popular idea is that a person’s mental illness must be completely overcome—as in, no more symptoms, ever—before that person can return to work. Both Lynde and SAMHSA’s Paolo del Vecchio dismissed that notion.

“We need to break the Prozac ceiling,” del Vecchio said. “Individuals with mental illness don’t have to become less symptomatic before returning to work. Work, in fact, reduces our symptoms. Sustained unemployment and inactivity do not.”

“I’d love to see the workplace that doesn’t have somebody working there [with mental illness],” Lynde said. “If we operated under the premise that we all had to be symptom-free to go to work, most of us would go home.”

4 INTEGRATED CARE AND WELLNESS



“Our problem right now with the medical care system is the fragmentation of the mind from the body, the body parts from the body, and the person from [his or her] social and cultural, vocational context combined with their professional center of care. Could we do any worse? ... What we really need is ... an approach that allows many voices to come together.”

—Daniel Fisher, Executive Director, National Empowerment Center

One day a patient of Daniel Fisher, a woman he'd treated for more than three decades, walked into his private psychiatric practice in Massachusetts to ask for help. She couldn't sleep. She was fighting paranoia. She feared another psychotic episode (and the hospitalization that might follow). Fisher saw an opportunity to try a technique he'd been reading about called “open dialogue.” He asked the woman to come back with her husband, with friends or other family members, with anyone (including other health care professionals) who might have knowledge or perspective on the woman's situation.

Turns out her stress was due to the overbearing demands being put on her husband, who had begun running a restaurant as a second job, on top of his regular nine-to-five. The husband had a history of cardiac disease, diabetes, and sleep apnea, and the strain was taking its toll.

“I called his ‘sleep doctor,’ as [the husband] called him, a neurologist at a very eminent teaching hospital in Boston, and I said, ‘Do you know what's going on?’” Fisher recalled. “‘He's having trouble sleeping.’ I said, ‘Do you know why?’ He said no. I said, ‘Well, he's taken on a restaurant. He's been doing that and [working] full time. He said, ‘Oh my gosh, of course he's having trouble sleeping.’

“I said, ‘Does his cardiologist know?’ He said, ‘Oh no, his cardiologist doesn't know.’ I said, ‘Does his diabetes doctor know?’ ‘Oh no, they don't know. As a matter of fact, none of us ever talk to each other.’”

If holistic health care—that is, a care model that does not isolate particular functions or conditions but rather takes into account the complete person—holds great promise for “healthy” individuals, it is even more important for those suffering from mental illness. In every symposium session, speakers stressed the need to link not just mental and physiological health care but all support services together to promote effective recovery. From Australia's “joined-up solutions,” as described by David Cappo, to the “health in all policies” philosophy currently being championed by multiple

U.S. medical and public health agencies, it's clear that an integrated approach to health and wellness is gaining currency worldwide and across the care spectrum.

“Locally, it's become common practice for community mental health centers to at least screen for common cardiovascular problems: high blood pressure, cholesterol, diabetes,” said psychiatrist and public health professor Benjamin Druss. “There are mental health centers that have become federally qualified health centers; a classic example, a kind of mecca of integrated care, has been Cherokee Health System in Tennessee.”

A System in Need of Repair

But we're not there yet. In fact, despite recent isolated success with techniques like open dialogue—not to mention the hundreds of billions of dollars poured into it each year—the U.S. health care system endured far more criticisms than compliments over the symposium's day and a half. From the stigma and biases displayed by health care practitioners themselves, to the predominance of normative practices not based in the latest evidence, to the system's stubborn resistance to change and finally to the fact that significant components of it are set up to reward failure in terms of outcomes, American health care regarding those dealing with mental illnesses was put under the microscope and often found wanting. And several speakers pointed directly at where practitioners learn their trade.

“The training system for health professionals in general, and for doctors in particular, is antiquated and largely based on a model that was developed about 100 years ago,” Druss said. “We have to recognize that part of our goal, if we're going to improve medical care, is going to require some fundamental reworkings of the medical education system.”

“We need to offer people with mental illness the treatment that works: evidence-based practices,” said administrator Gretchen Grappone. “I'm really proud that I work at an agency that provides evidence-based practices, including supported employment. We need to emphasize the teaching of evidence-based practices in colleges and universities where students are learning

to become social workers, psychologists, occupational therapists, and other health care professionals.”

Perhaps most pernicious among the U.S. health model's problems is its tendency to focus on (and reward) disease management rather than overall health and wellness. This extends not simply to providers but to consumers themselves, as speaker after speaker—particularly those with lived experience—referred to the “Social Security trap,” meaning those mental health consumers who are reluctant to take steps toward recovery, such as employment, for fear of losing their disability benefits.

“The Social Security disability trap, we see time and time again, keeps people in their illness—it keeps people out of control [of themselves] and not able to realize their full potential or to use their talents and become contributing members of society,” said mental health administrator Peggy Swarbrick. “We forget to tell people [who become dependent on these benefits] that you will be in poverty. You will be at the mercy of the mental health system for the rest of your life. If you continually live in that state of dependency, we think that's ‘part of the illness’ but it exacerbates their sense of not being in control. It's not positive for people's mental and emotional well-being, whether they have a so-called diagnosis or not.”

Even medication came under scrutiny. By no means was it accepted at this symposium as the first, best answer for all individuals dealing with mental illness. And even when it is warranted, several speakers stressed that consumers must freely accept a medication regimen. Fisher, for example, called it an “unchallenged assumption”—one that colors all care decisions made in the United States, he said—that long-term outcomes in all cases are improved by medications. SAMHSA's Paolo del Vecchio said individuals must be empowered to challenge that assumption themselves.

“Psych meds have serious side effects, as we all know, and add to the risks for morbidity and early mortality,” del Vecchio said. “Medication use must be a personal choice, and consumers need to be informed and involved in their own health care.”

No Individual Has the Illness

To that end, in 2012 SAMHSA added an online decision guide for antipsychotic medication to the already extensive resources on its website. The guide, del Vecchio explained, is meant to help mental health consumers make informed decisions about their medications, and as of the Nov. 1 symposium it had been downloaded some 16,000 times. SAMHSA also has made nearly 100 grants to local agencies through a behavioral health care integration program, which one Pennsylvania study showed to help reduce hospital admissions and ER visits for adults on Medicaid.

Consultant David Lynde shared his own success stories from Dartmouth's Evidence-Based Practices Center, whose supported employment model integrates with local health providers. And Druss pointed to the Carter Center's own work that seeks to help build partnerships between mental health centers and federally qualified health centers. The Emory professor offered a hopeful vision of coordinated care across "virtual homes" spanning several supporting organizations.

"We as a behavioral health community are actually, I believe, out ahead of the curve on this issue of how to do a better job of providing coordinated care for complex and challenging patients," Druss said. "The lessons we learn ... will be able to be taken more broadly to the medical field, to understand how best to serve these populations, including how to work across organizations."

Definitely ahead of the curve is Fisher's open dialogue approach, though perhaps through a Foundation for Excellence in Mental Health Care grant he can help the rest of the country catch up. The grant, Fisher said, will allow him to create a curriculum for instruction in open dialogue, which he calls "the best of family therapy, systemic therapy, network therapy, and need-adaptive therapy." Open dialogue, essentially, lifts the stigma from the illness by connecting individuals more strongly to their human support system.

"They started with a hypothesis," Fisher said. "That is: No individual has the illness. It does not reside in any one person."

Hope Right from the Beginning

"Talk of social inclusion must include the social implications of entering treatment," Fisher said. "Let's address diet, exercise, trauma, sleep, employment, family dynamics, and spirituality first, before only looking toward medical labels. We need a dynamic, whole-person model that builds community, expands social networks, and moves us toward social inclusion."

Regardless of their particular approaches, the 2012 symposium speakers all embraced that same end goal, and many didn't simply embrace it—they lived it. Despite all the challenges they described in dealing with families, in navigating the labyrinth of care services and the bureaucracy of government, in countering resistance from frightened and uninformed communities, their stories provided inspiration through their own personal triumphs over stigma. Whether it was Elyn Saks' journey from the darkness and terror of her symptoms to the law faculty of a prestigious university, or fellow keynoter Graham Thornicroft's decades-long witness to his mother's recovery from hospitalization for depression, or the lived experiences of several other speakers, the stories shared onstage in the Carter Center Cecil B. Day Chapel proved Fisher correct when he assured: "There's always hope. There's hope right from the beginning. There's hope all the way through the course of one's life."

"A healthy America is within our reach when we stop thinking about behavioral health as only an attribute of individuals," del Vecchio said. "A healthy America is within our reach when we start addressing the social, economic, political, and cultural contexts that affect determinants of health."

"I'm proud to be the first self-identified mental health consumer to lead our federal government's mental health services agency. And I acknowledge that my success is, in fact, all of our success. It's an acknowledgment of how far we have come."

KEYNOTE ADDRESSES

Elyn Saks

Orrin B. Evans Professor of Law, Psychology and Psychiatry and the Behavioral Sciences, University of Southern California Gould School of Law

While writing her book, “The Center Cannot Hold: My Journey Through Madness,” Elyn Saks said she kept two goals in mind: to give hope to those who suffer from schizophrenia and understanding to those who don’t.

Saks did both in her opening keynote at the 2012 symposium, sharing a lived experience that’s taken her from the body restraints of East Coast psychiatric hospitals to a 2009 MacArthur “Genius” Award and a chaired appointment at the University of Southern California’s Gould School of Law. Saks read passages from her book, letting the audience inside her mind during the episodes that pulled her (temporarily) out of Yale Law School and into an involuntary hospitalization.

The next morning, I went to my professor’s office to ask for an extension on our memo assignment, and I began gibbering as I had the night before, and he eventually brought me to the ER. Someone I will just call the doctor and his whole team of goons swooped in, grabbed me, lifted me out of my chair, and slammed me down on the bed with such force that I saw stars. Then

they bound my arms and legs with thick leather straps. A sound came out of my mouth that I never heard before, half groan, half scream, pure terror.

But Saks did not give up. She returned to Yale—“It never occurred to me that I wouldn’t finish my degree.” She made it to Los Angeles and to the USC faculty. She married a supportive and loving husband. With her MacArthur grant she started the Saks Institute for Mental Health Law Policy and Ethics. Step by step, Saks built a productive, meaningful, and successful life, all the while battling the illness that she knew lurked close by, always.

“When the public sees people with mental illness thriving in the community, that dispels stereotypes and lessens stigma, and that in turn opens more doors and creates more opportunities. That’s the road we should be traveling,” Saks said. “What those of us who suffer from mental illness want is what everybody wants: in the words of Sigmund Freud, to love and to work.”

Note. To view Elyn Saks’ keynote address, visit www.cartercenter.org/health/mental_health/symposium/2012/archives2.html.

Graham Thornicroft

Professor of Community Psychiatry, Health Service and Population Research Department, Institute of Psychiatry, King's College London

Earlier in his career, when Graham Thornicroft first encountered and struggled against the all-too-frequent nimbyism that accompanies the placement of a new mental health facility, he grew frustrated. How could these local residents spend so much time blocking what he knew in his heart to be the right thing?

“But I’ve since changed my mind,” Thornicroft said in his second-day symposium keynote address. “I think these people are entirely reasonable in their behavior, entirely reasonable on the basis of the knowledge they have. They don’t know how common mental illnesses are. They don’t know how much we can treat them. They don’t know how [many] people in the community all around us do have mental health conditions.”

Rather than remain frustrated, Thornicroft decided to address the problem at its root through projects like the UK’s Time To Change awareness campaign. His keynote was punctuated by examples of the campaign’s short videos, designed alternately to educate the public about mental illness and encourage those dealing with conditions to talk about them and battle the isolation and fear of stigma. Thornicroft also described the survey methods used to measure stigma and thus the effectiveness of Time To Change.

“We have seen a wide range of modest positive improvement,” he said. “Again and again, there are two issues most closely associated with positive change: First, do you have direct contact with somebody with a mental health problem? Two, have you seen or are you aware of the campaign? Both together convey an even more favorable response.”

Thornicroft said he had three goals for his keynote: Frame the challenge of battling the stigma against mental illness, talk about the evidence for the effectiveness of interventions such as awareness campaigns, and offer some resources for those working in the field (he offered access to an Internet folder of some 50 research papers on stigma to anyone who emailed him). In doing all three, he made a passionate case for action, lamenting that the best national rate of treatment for those with mental illness belongs to the United States, which still treats only about a third of that population.

“The bad news is you’re ignoring two-thirds of all people with mental illness, and we’re doing even worse in Europe,” Thornicroft said. “This is not OK. We carry on as if the situation is pretty good, ‘Let’s make some incremental changes.’ But it is not OK. We are systematically disregarding and not treating a large majority of people with mental illness worldwide.”

Note. To view Graham Thornicroft’s keynote address, visit www.cartercenter.org/health/mental_health/symposium/2012/archives2.html.

POLICY RECOMMENDATIONS

Twice during the 2012 symposium attendees were invited to participate in one of several working groups, each charged with examining a different action area related to mental health care. The groups were asked to develop up to three policy recommendations informed by the perspectives of the specific group (e.g., research, services, public health, or law and policy). Each recommendation needed to be actionable and address either removing barriers to full access to community life or promoting social inclusion in the areas of housing, employment, or wellness and health care integration. The groups were asked to identify the following:

- What tools or information would we need to promote or implement the recommendation?
- What barriers or obstacles would we need to overcome?
- What entity (e.g., governmental, nongovernmental, research, advocacy) should be responsible for implementing and monitoring each recommendation?

Here's what the groups identified:

Services

1. Encourage integration and better recovery-oriented systems by streamlining Medicaid payments and processes. Some examples: Allow same-day billing for mental health and physical health visits; have equal prescription costs for federally qualified health centers (FQHCs) and community mental health centers (CMHCs); reimburse for care coordination.
2. Direct the U.S. Department of Education to work with SAMHSA and the Administration for Children and Families to develop standards for teacher education curricula. Encourage the National Council for Accreditation of Teacher Education to require this as an inclusion of teacher education programs and training.
3. Direct SAMHSA and other government agencies to increase focus on integrating recovery-oriented behavioral health services into primary care and develop guidelines to promote use of recovery-based language and practices.

Public Health

1. Ask the mental health community to rally their support for the current Healthy People 2020 objectives because they already relate to people with mental illnesses.
2. Propose new objectives for Healthy People 2020 over the next decade.

Research

1. Study the dissemination of the latest research in mental health care and direct that all research proposals include actionable plans for dissemination.
2. Require that mental health program funding include an evaluation component that includes continuous quality improvement and sustainability strategies.
3. Require consumer involvement in research design, conduct, analysis, and interpretation.
4. Conduct additional research on how mental health consumers successfully achieve independence in employment, housing, and other dimensions of social inclusion.

Law and Public Policy

1. Implement the U.S. Affordable Care Act, thereby supporting continued efforts to improve health care at the federal and state levels, by doing the following:
 - Fully fund all required components of the law
 - Ensure access to timely and appropriate services
 - Ensure equal benefits for beneficiaries in both Medicaid and Medicare expansion efforts
 - Include in the essential health benefits package services and supports based on evidence-informed practices, including psychosocial rehabilitation tools
 - Align reimbursements and incentives with recovery and recovery-focused outcomes
2. Regulate health care such that behavioral health care is delivered at parity with other health care.
3. Have the White House issue an executive order requiring all federal agencies to coordinate the government's efforts to promote integration and inclusion, and form a presidential commission on social inclusion.

RESOURCES

The following selection of organizations, websites, and books were cited during the 2012 Rosalynn Carter Symposium on Mental Health Policy.

Organizations

U.S. Substance Abuse and Mental Health Services Administration (samhsa.gov)

Disclosure Conversations document

Primary Behavioral Healthcare Integration program

Million Hearts Campaign

2012 National Strategy for Suicide Prevention

Shared Decision Making tools

Recovery to Practice tool

National Alliance on Mental Illness (nami.org)

In Our Own Voices program

Bring Change 2 Mind (bringchange2mind.org)

Foundation for Excellence in Mental Health Care (femhc.org)

Saks Institute for Mental Health Law, Policy, and Ethics (weblaw.usc.edu/centers/saks)

Hearing Voices Network (hearing-voices.org)

Time To Change (time-to-change.org.uk)

Mind (mind.org.uk)

Rethink (rethink.org.uk)

Families for Depression Awareness (familyaware.org)

Active Minds (activeminds.org)

A Way Home for Tulsa (csctulsa.org)

Mental Health Association in Tulsa (mhat.org)

New Jersey Institute for Wellness and Recovery Initiatives (welltracc.org)

Dartmouth Evidence-Based Practices Center (prc.dartmouth.edu/ebp)

National Empowerment Center (power2u.org)

Books

The Center Cannot Hold: My Journey Through Madness, by Elyn Saks (Hyperion, 2008)

Shunned: Discrimination Against People with Mental Illness, by Graham Thornicroft (Oxford Press, 2006)

The Day the Voices Stopped, by Ken Steele & Claire Berman (Basic Books, 2002)

An Unquiet Mind: A Memoir of Moods and Madness, by Kay Redfield Jameson (Vintage, 1997)

Undercurrents: A Life Beneath the Surface, by Martha Manning (HarperOne, 1995)

The Family Guide to Mental Health Care, by Lloyd Sederer (W.W. Norton & Co., 2013)

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