Could you detail what first led you to focus on this field of research?

The understanding of stigma is a classic problem within the field of social sciences and mental illness. It is perhaps more significant in mental illness than any other arena, except race, and quickly developed into issues of prejudice and discrimination. Initially, however, I was not fundamentally interested in this issue. I began by trying to understand how individuals who develop mental health problems cope with onset. In particular, I was frustrated with the dominant models at the time that focused on the individual and their mental attitude towards treatment. While the models developed our understanding of this area, they weren’t so successful in determining which individuals would require full-time mental health services.

With a focus on human connectedness, I proposed a framework that targeted the influence of social networks around the person with the health problem. This had two effects: it drew attention to the different social pathways that individuals travelled, and took into consideration the community ties that provided advice, helped them to understand their problems, etc. Social networks carry not only influence but also culture – ideas, beliefs and attitudes about how to respond.

Stigma and its connection to culture has been a topic for discussion since ancient times. When exploring research that was conducted in the early 1990s, I repeatedly came across statements such as: ‘Now that stigma has dissipated’. This struck me as peculiar. Having just spent months in psychiatric units for my previous research project, I had experienced no lessening or dissipation of stigma. I then started researching current understanding of the stigma that surrounds mental health in the US and discovered that a national study of the larger cultural climate hadn’t been conducted since the 1950s.

The question of whether stigma exists belongs to social science and culture, not to psychiatry or neuroscience. So, along with a team from Columbia University (where Dr Bruce Link had previously conducted important work on experiences of prejudice and discrimination reported by individuals with mental illness), a team from Indiana University proposed the first National Stigma Study, which was fielded in 1996. The findings were clear: stigma was still prevalent within US culture.

Since that time, we have taken on the issue of children’s mental health and also replicated the original adult study in 2006. Given the resurgent interest in stigma around the world, which was initiated when psychiatrist Norman Sartorius became President of the World Psychiatric Association, the obvious next step was to research stigma across the globe.

Supported by the US National Institutes of Health (NIH) and research institutes in many other countries, eg. Rannis – the Icelandic Centre for Research (Sigrun Olafsdottir); Ghent University (Piet Bracke), we initiated the Stigma in Global Context – Mental Health Study (SGC-MHS). The US team met in Madrid in 2004 with our international collaborators to finalise the instrument that would be fielded on a representative sample of the public in each selected country. Our work in China came later when one of our colleagues, Ethan Michelson, a scholar of Chinese Law, approached his colleagues at Renmin University in Beijing. Today, the SGC-MHS has collected data from 17 different countries across six continents.

Professor Bernice Pescosolido reveals the original impetus and current goals of her research on the prejudice and discrimination – more commonly referred to as stigma – which surround mental illness. She also discusses how her work is being used to provide a scientific basis for Bring Change 2 Mind, an organisation whose goal is to end stigma.
Against this context, what aspects of this work do you find most rewarding?

We have been able to dispel many myths that have marred quality of life for people with mental illnesses, their families and those who care for them in treatment systems. The resurgent interest in stigma has not only focused on public culture but has also targeted self and provider-based stigma.

For our part, we have found the ‘backbone’ of stigma, which reveals the heart of prejudice and discrimination endorsed by every society we have studied. After determining that over the last 10 years in the US, understanding of the causes and the efficacy of treatment of mental illness had improved but there had been no change in approaches to stigma, we became part of a movement to take new directions in stigma reduction. Through organisations like Bring Change 2 Mind (BC2M), we have used scientific findings to help advocates develop messages about mental illness that might be more effective in reducing stigma.

Could you expand on the impact of recent ‘black box’ warnings on US antidepressants on prescriptions for adolescents and children?

We have no direct data on the impact of these warnings. However, our research can provide some interesting information on the public perception of psychoactive medications. In our 1998 National Study, we asked a series of questions on medication as an option for mental health problems. Overwhelmingly, the US public sees these medications as effective. However, they do support the use of psychoactive medication for others while exhibiting a reluctance to take it themselves.

Your research uses data from various countries around the world. What differences in cultural conceptions of mental illness have you found through the SGC-MHS?

We do see, despite the backbone of stigma, that there are significant differences in the levels of stigma around the world. In fact, we are currently preparing an analysis on whether the commonplace belief that stigma is related to a country’s level of development can be supported, or whether this is merely a myth. This is important because it can help us to contextualise and target the reduction of prejudice and discrimination against mental illnesses.

Your current investigations focus on the stigma attached to mental illness in Chinese society. What ultimate impact do you hope the research will have in this respect?

The SGC-MHS is designed to chart the global landscape of stigma. We want more information on the problems faced by all individuals with mental health issues but we also want to know which specific problems may be present within particular societies. By investigating China, we were able to move from representing 20 per cent to 40 per cent of the world’s population. Furthermore, the situation in China reveals yet another form of stigma: a kind of prejudice of mental illness that originates from the political situation.

Could you give some examples of how successful US campaigns to reduce stigma about mental illness have proved? What challenges have these campaigns faced and how are you applying these within a Chinese context?

Our job is to conduct analyses and be available to any group who would like to create a campaign. We have advised the Carter Center Mental Health Program and the California Mental Health Services Authority (CalMHSA), in their use of funds from a ‘millionaire’s tax’ to build an effective community-based mental health system and reduce mental health stigma and discrimination. Of course, my most direct work has been serving as Chair of the Science Advisory Committee for BC2M.

Until recently, there has been a lot of work to reduce stigma but there have been very few attempts to gauge the effectiveness of these efforts. We have now begun to build a scientific foundation to design and evaluate these anti-stigma campaigns. This approach is in its very early stages, even in the US. We have not yet done enough to be able to advise those campaigns in China.

Have you been involved in any events that you wish to highlight?

In June, I was privileged to attend the White House launch of a new dialogue initiative on mental illness. In September, I attended the Voice Awards at Paramount Studios. The Awards honoured those writers, producers, actors and others who have been central to correcting the image of people with mental illness. The media is often the primary or only source of knowledge for those who don’t have a relationship with someone with mental health problems. It is critical that the old images of the ‘homicidal lunatic’ are replaced with realistic images of people struggling with and overcoming the challenges of mental health problems. I would especially like to see the inclusion of individuals who ‘just happen to have’ a mental health issue, without it being central to their character.

**A TIMELINE OF MENTAL ILLNESS STIGMA STUDIES:**

<table>
<thead>
<tr>
<th>Year</th>
<th>Event</th>
</tr>
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<tbody>
<tr>
<td>1950</td>
<td>NORC Survey 272 (Shirley Star – reported as The Public’s Ideas About Mental Illness)</td>
</tr>
<tr>
<td>1957</td>
<td>Study of Modern Living</td>
</tr>
<tr>
<td>1960</td>
<td>Study of Modern Living</td>
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<td>1970</td>
<td>Study of Modern Living</td>
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<tr>
<td>1976</td>
<td>Study of Modern Living</td>
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<tr>
<td>1990</td>
<td>1996 National Stigma Study (NSS)</td>
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<tr>
<td>1996</td>
<td>1998 Pressing Issues in Health and Medical Care (NSS-Psych Meds)</td>
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<tr>
<td>2000</td>
<td>2002 National Stigma Study – Children (NSS-C)</td>
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<tr>
<td>2002</td>
<td>2004-2010 Stigma in Global Context – Mental Health Study (SGC-MHS)</td>
</tr>
<tr>
<td>2006</td>
<td>2006 National Stigma Study – Replication (NSS-R)</td>
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<tr>
<td>2011</td>
<td>2011 SGC-MHS China</td>
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</tbody>
</table>
Researchers from Indiana University and Columbia University have been investigating attitudes towards mental illness within the US. The subsequent Stigma in Global Context – Mental Health Study, developed by the Indiana University team, has expanded the scope for understanding mental health stigma worldwide.

According to the World Health Organization (WHO), one-third of citizens in most countries require diagnosis of one or more of the common mental disorders at some stage in their lives. Against this context, the American Journal of Psychiatry published a report conducted by teams from Indiana and Columbia Universities that compared US national surveys from 1996 and 2006 on the population’s attitudes towards mental illness. Data collected from nearly 3,000 US citizens showed that there had been an increase in the attribution of mental disorders to biological causes. Up from 57 per cent in 1996, 67 per cent of people attributed major depression to neurobiology. Regarding schizophrenia, the same statistic increased from 76 to 86 per cent, and for alcoholism, from 38 to 47 per cent. These results indicated that more Americans now understood that mental health problems are ‘real’ and require treatment. Many also thought that they should be treated with prescriptions and medication.

However, an increase in understanding of the causes of mental illness has done nothing to dispel stigma. Most people, for example, said they would not want a person diagnosed with schizophrenia or depression to marry into their family, suggesting an inclination towards connecting biological disorders with genetics.

**FINDINGS TO DATE**

Led by Professor Bernice Pescosolido and her co-investigators Jack K Martin and J Scott Long, the research has already determined that the standard kinds of group characteristics, such as gender, education and political views, are in fact not so useful in understanding which people may hold stigmatising attitudes and beliefs. Instead, it appears that there are constellations of cultural perceptions that group together and affect a person’s overall outlook. These perceptions include whether they know someone with a mental illness, how they respond to a set of symptoms and which situations they personally consider to be mental health issues. The new findings have provoked a shift in terms of policy and treatment of mental illnesses.

**COMPARATIVE OBSERVATIONS**

As part of their US data collection process, the team travelled to the University of Chicago and the University of Michigan to retrieve relevant survey data from the 1950s and 1970s. While innovations in modern psychiatry limited the usefulness of much of these data, the team was able to extract relevant information and cross-reference it with their own findings from the 1990s onwards. The findings revealed both positive and negative trends. Americans have become more knowledgeable, sophisticated and open about discussing mental health problems. However, they also suggested dangerously high levels of stigma, and in some cases even demonstrated a regressive attitude towards individuals with mental health issues within social contexts.
BRING CHANGE 2 MIND  WWW.BRINGCHANGE2MIND.ORG

Bring Change 2 Mind (BC2M) is a US national anti-stigma organisation, founded by actress Glenn Close, which aims to end stigma and discrimination surrounding mental illness. The focus of BC2M is on social inclusion. The organisation aims to improve quality of life for people with mental health issues and their families by raising awareness about mental illness and trying to change the way society looks at those experiencing these devastating illnesses. BC2M encourages sharing personal narratives, distributes helpful advice and information and also acts as a gateway for many other organisations that provide information, service, screening, support and treatment of mental illnesses. The organisation is partnered with the ‘Time to Change’ campaign in Great Britain. Pescosolido currently serves on the Board of Directors and is Chair of the Science Advisory Committee for BC2M.

Currently, there is no routine data collection on mental illness stigma in the US or most other countries worldwide

STIGMA IN GLOBAL CONTEXT – MENTAL HEALTH STUDY

In 1996, the World Psychiatric Association, led by Norman Sartorius, created an anti-stigma programme entitled ‘Open the Doors’ that drew attention to the problems of mental health stigma. However, the Stigma in Global Context – Mental Health Study (SGC-MHS) is the first worldwide study to compare different cultural climates and their effect upon individuals with mental health issues.

The SGC-MHS was conceived in response to a question posed by the International Study of Schizophrenia – why do individuals in ‘developing’ countries report better outcomes than those in ‘developed’ countries? The study is funded by the US National Institutes of Health (NIH) and aims to assess levels of mental health stigma within different societies, comparing them worldwide.

Using a multidisciplinary and multi-level theoretical framework, the SGC-MHS is the first globally coordinated study of the social, political and cultural climates that affect mental illness. It utilises a vignette-based survey to assess the public’s reaction to people with mental illnesses, data that can be used to provide better public health and treatment systems as well as mitigate negative social environments for individuals with mental health problems. So far, data from 17 countries are in the SGC-MHS database. These countries span a wide range of economic backgrounds and a variety of different cultures, such as Great Britain, Germany, Hungary, Cyprus, Argentina, South Korea, Brazil, South Africa, Bangladesh and the US. Several others are interested in joining the study or have joined with a modified survey design.

COLLABORATIVE PROJECTS

Collaboration is essential to the work of Pescosolido and her team. Their efforts aim to reach out to people who are or have been affected by mental illness, their families, advocates, doctors, policy makers and researchers who work with mental health issues. Their study considers the perspectives of scientists across the spectrum of research fields. These include, but are not limited to, sociology, psychology, nursing, psychiatry, anthropology and social work. Researchers from different disciplines are critical in order to identify the complex roots of the problem and propose effective solutions.

FUTURE PLANS

New neuroscientific research is essential to deepening understanding of the underlying causes and most effective treatments of mental illnesses. However, in delivering care, providers must understand the potential of stigma to interfere with the treatment process and integration into the community of persons with mental health issues.

The researchers plan to continue monitoring stigma within the US. Currently, there is no routine data collection on mental illness stigma in the US or most other countries worldwide. In England, the ‘Time to Change’ campaign has begun to monitor levels and change, although this is still a relatively recent development. The ongoing collaborative work will contribute towards an improved understanding of mental health issues and counteract stigmatising attitudes, beliefs and behaviours. Ultimately, the SGC-MHS demonstrates that, like neuroscience and clinical and genetic research, social science research is a critical part of improving the lives of those with mental illness and the mental health treatment system.

STIGMA OF MENTAL ILLNESS IN CHINA: EXTENDING THE STIGMA IN GLOBAL CONTEXT – MENTAL HEALTH STUDY

OBJECTIVES

• To estimate the nature, level- and individual-level correlates of stigma in China using a tailored version of the SGC-MHS Study instrument

• To use the survey data collected by the Chinese module of the SGC-MHS to test hypotheses concerning the influences of barriers, particularly stigma, to the endorsement of medical and mental health services

• To integrate the data from the Chinese module of the SGC-MHS into the larger 16 nation study to examine the causes and correlates of stigma

KEY COLLABORATORS

Dr Ethan Michelson, Indiana University
Dr Jack K Martin, Indiana University
Dr J Scott Long, Indiana University
Dr Weidong Wang, Renmin University of China

FUNDING

National Institute of Mental Health – grant no. R01MH82871

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BERNICE A PESCOSOLIDO, Distinguished Professor of Sociology, Indiana University, is Director of the Indiana Consortium for Mental Health Services Research. Her research focuses on social issues in health, illness and healing – assessing how social networks connect individuals to their communities and to the treatment system. Pescosolido has received funding and/or served on advisory groups for the National Institutes of Health, MacArthur Foundation, Robert Wood Johnson Foundation, The Carter Center and Bring Change 2 Mind.

INTELLIGENCE