

BY REBECCA G. PALPANT

# Bridging the Gap in Stigma Research to Build Better Mental Health



Photos courtesy © Eugene Richards

Today, we can map the course of a seizure as it travels across the brain or pinpoint where memories exist in the inner recesses of the mind. We have medicines that are so technically advanced they target specific types of neurons. The genetic and biological causes of some mental illnesses have been identified after

decades of research. Despite all of this progress and the tremendous growth in availability of cost-effective treatments, we still know so very little about how to prevent or reduce the stigma against mental illnesses, which can be as damaging to a person's health and well-being as the illness itself.

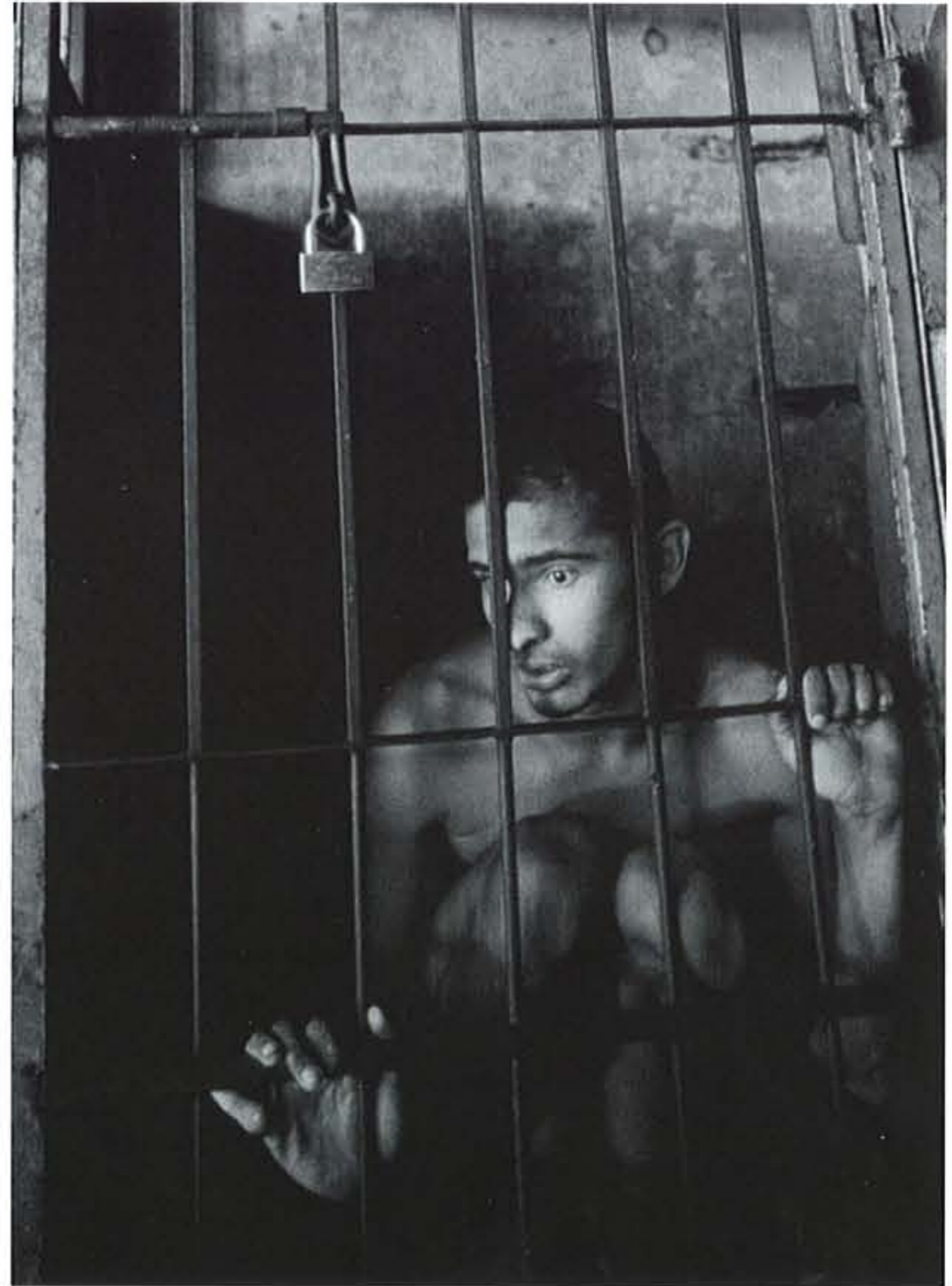


Stigma, a mark or label that leads to discrimination, remains one of the greatest barriers to people seeking treatment worldwide. Stigma against mental illnesses is linked with heinous forms of discrimination and human rights abuses, with some of the most disturbing violations taking place in psychiatric hospitals. In both developing and wealthy nations, mental health services and institutions are chronically underfunded and understaffed, functioning largely as crumbling warehouses for the suffering rather than providers of rehabilitative care.

Mental illnesses are some of the most expensive and disabling conditions – they represent five of the top 10 leading causes of disability worldwide for men and women in their prime. Stigma and discrimination often define the barriers that prevent so many from accessing less costly and effective early interventions critical to maintaining a productive and meaningful life. If millions of people in both developed and developing countries could access appropriate mental health treatment without fear of labeling or discrimination and remain as productive and contributing members of the community the economic benefits to communities would be countless.

The Movement for Global Mental Health, BasicNeeds and The Carter Center, among many other mental health groups, are working to identify innovative ways to address the barriers to providing evidence-based treatments where mental illnesses are highly stigmatized and discrimination is pervasive. In Liberia, for example, approximately 40 percent of the population is believed to suffer from a range of mental health disorders, including post-traumatic stress disorder (PTSD), after a long and brutal civil war. The Liberian Ministry of Health and Social Welfare has committed to improving mental health in the nation but faces many challenges not the least of which, according to preliminary research conducted by The Carter Center, are prevailing myths on the causes of PTSD. For example, there is a belief that PTSD is caused by having committed a crime or wrongdoing during the war, and that those who suffer from it deserve such a punishment.

In developing countries, stigmatizing attitudes are more widespread across various illnesses and not necessarily associated with just mental health. But the myths and misunderstandings about mental illness are just as concerning in developed nations. In many parts of the developed world, violence and serious mental illnesses are perceived as inextricably linked, perpetuating the stereotype that people with mental illnesses are to be feared with very little evidence to support a significant relationship. In fact, data indicate that people with



mental illnesses are far more likely to be violated than those without the experience of mental illness.

Great strides have been made in the field of mental illness stigma research over the past decade through the efforts of many people that have devoted their careers to this issue. But much more needs to be done. We are learning a great deal about how to increase knowledge and understanding of mental illnesses – more people now believe in the effectiveness of treatments. Progress, however, in the area of changing attitudes and behaviors has been challenging.

Finding ways to advance quantitative research in the area of stigma research could advance the field in new and bold ways. More work is needed to build outcome measures for methods to address the intractable problem of stigma and discrimination associated with mental health problems. Millions of dollars and the hard work of untold numbers of consumers and advocates continue to drive wide-reaching anti-stigma campaigns in many countries. We must do better in providing the evidence to support anti-stigma messages and initiatives not only to validate their effectiveness, but also to ensure that they aren't doing more harm than good. Recent findings indicate that touting mental illnesses as



brain diseases – “a disease like any other” – in some cases has inadvertently encouraged the belief that there is nothing one can do to prevent these diseases. The impetus behind the approach was to help people understand the physical component of mental health using general health terminology, but instead, it led people to believe that the illnesses are permanent, leading to the notion that nothing should be done 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).

### GAPS IN THE RESEARCH

The field of mental health stigma research is in its infancy, and only recently has research begun driving a comprehensive and well-defined agenda to improve our knowledge base on this issue. Of paramount importance is the development of consistent measures endorsed by the field. Critical to the success of these endeavors is the establishment of an outlet for information exchange of projects that select a problem, define it, determine how to measure it, create a program to address the problem, and measure the results and outcomes. The Carter Center is an affiliated organization with the journal *Stigma Research and Action*, launched in January 2011, that provides one of the first such formal venues to share this information.

The future directions for the field should center on a demonstration of cause and effect relationships. By changing knowledge and attitudes about mental illnesses, can behavior consequently be changed? Additionally, how might positive behaviors be enhanced instead of focusing on stopping negative ones? The most pressing question is how to address the perceived connection between mental illnesses and violence, which is one of the most significant causes of stigma and discrimination against these disorders.

The media play a key role in perpetuating these stereotypes and more work should be done on how best to inform them about inaccurate depictions as well as going further to encourage sensitivity and balance. The Rosalynn Carter Fellowships for Mental Health Journalism is an ongoing initiative to encourage journalists to explore a timely mental health topic over

the course of a year and complete a major media project connected to their work. The field could benefit from the evaluation of other mental health and media initiatives to assist in guiding further development of these important programs.

Those with the lived experience of mental illness can provide critical “on the ground” information and insights that are invaluable, but not often sought by the field. This sizeable gap provides a major barrier to progress, and mental health consumers must inform future thinking and directions in the field. Their voices can be the best guides in identifying targets for stigma research as well as desired outcomes.

### FUTURE DIRECTIONS

Critical to the success the field of mental illness stigma research has achieved over the past decade have been the key partnerships and coalitions formed globally. There are lessons to be learned from other stigmatized health conditions and public health campaigns, and they should be shared in a structured and consistent process. The field holds substantial professional opportunities for the next generation of bright and innovative researchers if they can be engaged and their interest cultivated.

Other areas for further exploration include an examination of the contribution of mental health professionals on perpetuating or reducing stigma, exploration of attitudes of children, and increase in evaluation research. The field could benefit from further exploration of the use of direct observation in research methodology.

The next decade of mental illness stigma research has the potential to be the guiding force in measuring and re-shaping stubborn attitudes and behaviors that have been intractable for generations. The knowledge-base has been laid, partnerships have been cultivated and developed, and key measurement tools have been identified. With these critical factors in place, it would be unconscionable if the field does not leverage the opportunity at this critical point to propel stigma research forward and ultimately to make a difference in how people with mental illnesses are perceived and treated within their communities. **GH**