Understanding the Stigma of Mental Illness: Theory and Interventions

Edited by

Julio Arboleda-Flórez
Queen’s University, Ontario, Canada

and

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University of Geneva, Switzerland

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Foreword

The World Health Organization has estimated that 450 million people today suffer from mental or behavioural disorders, or from psychosocial problems such as those related to alcohol and drug abuse. Many of them suffer alone and in silence. Many never receive treatment of any kind. Between them and the prospect of care stand the barriers of stigma, prejudice, shame and exclusion.

In Latin America and the Caribbean, as everywhere else in the world, the burden of mental disorders has become too large to ignore. Current data likely underestimate the numbers of untreated people but even for the acknowledged numbers, there is a wide gap between the need for and provision of mental health care. Changes in the population structure will only widen this treatment gap unless remedial policies can be formulated and implemented.

The World Health Organization and the Pan American Health Organization have issued this emphatic statement: Mental Health, neglected for far too long, is crucial to the overall well-being of individuals, societies and countries and must be universally regarded in a new light.

The stigmatizing of, and discrimination against, people with mental disorders is as old as humanity, but there has never before been a Zeitgeist, a moment, a social group, or the political will to focus on finding solutions, such as there is today. This new determination to resolve problems may be related to the realization that mental illness does not respect age, race or socio-economic status and that, in any country, a large proportion of the population will be affected by mental health. Mentally ill people and their families need treatment, social services and enlightened policies to manage their conditions; their needs can no longer be ignored. Moreover, the economic impact of stigmatization upon medical resources, as well as upon absenteeism in the labour force, also demands attention. Researchers, clinicians, policy makers, those affected and their families seem to be of one mind - it is time to find solutions.

That stigma and discrimination exist is not in question. It is known that stigma and discrimination negatively affect the treatment and recovery of people with mental illness. There are moves to combat these but such interventions themselves require evaluation so that we can learn what has an effect and what does not. What need to be more clearly elucidated are ways to measure stigma and discrimination and then ways to determine which treatment strategies are most effective. Scales to measure stigma have to be devised and tailored to measure this social construct among the stigmatizers, which might be the whole of the society, including even the mentally ill themselves (for self-stigma is a major block to recovery). Four intervention methods are commonly recognized – literacy campaigns, protest actions, contact enhancements and political activism to protect the civil and political rights of patients. The impact and effectiveness of these methods need to be evaluated.

This book is utopian in the sense that it has been conceived as a way to start doing more about measuring stigma and discrimination and about intervening to break the cycle of
despair that these produce. The book, therefore, is not about what stigma and discrimination are, or their impacts, but about the best ways to measure them and how to reduce them. The book contains theoretical chapters to frame the issue, but most address measurement and interventions. As such, the book is directed at anti-stigma practitioners, researchers and clinicians. It should be a resource for academics and students intent on learning more about these issues and, last but not least, a guide for policy makers and administrators interested in improving the way people with mental illness are managed in clinical settings and in the community. The book is a call to action and a cry for the inclusion of the mentally ill in our society.

I am pleased to present this book to you and to recommend it to the public health community and other members of society involved in this subject. The Pan American Health Organization acknowledges and appreciates the contribution of this distinguished group of experts. I hope that this excellent and useful book will help hasten the urgent changes that are needed in our region.

Dr. Mirta Roses Periago
Director, Pan American Health Organization
Preface

The editors and the majority of those who contributed chapters to this volume worked together for a number of years in the largest ever international programme to combat stigma and discrimination caused by a disease. The programme, initiated as an Institutional Programme of the World Psychiatric Association (WPA) in 1996, assembled teams in some twenty countries, and experts from many more\(^1\) to fight stigmatization and discrimination against schizophrenia sufferers. The programme was highly successful in many of its settings and is still running in a number of the countries originally involved, as well as in others that joined later.

Reflecting these origins, this volume contains two types of chapters: those dealing with theoretical issues (chapters by Arboleda-Flórez, Stuart, B. Schulze, H. Schulze, and Yang and his colleagues), and those reporting on experience from some of the settings of the WPA programme – the chapters by López-Ibor and colleagues, Baumann and colleagues, and Üçok and Warner. Sartorius describes the WPA programme as a whole and summarizes some of the main lessons learned during its first 10 years. One chapter has been contributed by an author who did not participate in the WPA programme – Pescosolido discusses a major investigation of attitudes to people with mental illness, bringing together data from a variety of countries.

In the chapters dealing with theoretical issues, emphasis has been placed on problems of measurement in anti-stigma programmes, starting with an historical overview of measurement approaches. These chapters describe the assessment of the needs which an anti-stigma programme should attempt to address, strategies for evaluating such efforts and the use of advanced information technology in their conduct. Of the chapters reporting country-specific issues, two address an issue that has received insufficient attention in the past – the role of health care staff in stigmatization – while one reviews the way in which a number of centres collaborated in establishing anti-stigma initiatives simultaneously over several locations in Germany.

The main message of the volume is that it is possible to carry out successful programmes against stigma and that a robust collection of interventions has been developed in parallel with the relevant technology of measurement and evaluation. The question today is no longer whether we should fight stigma – we must because stigma remains the main obstacle to any mental health programme – nor even how this should be done. The focus has shifted to the choice to be made, by individuals and societies – to do something about stigma or to close their eyes both to the need to act and to the options for effective intervention that are at their disposal.

The authors and editors hope that this volume will spur individuals and societies to act.

Julio Arboleda-Flórez
Norman Sartorius
December 2007

1 The rights of a powerless legion

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Introduction
The most frequent contact the general public has with mental illness is through the media or by direct observation in the busy streets of large cities of derelicts, most of whom are mentally ill. Unfortunately, media portrayals of mental patients usually relate to them as unpredictable, violent and dangerous. The association between mental illness and violence is only one of the many negative stereotypes and prejudicial attitudes held by the public about persons with a mental illness. Direct observation of mentally ill persons in the streets further cements the stereotype that mental illness causes an inevitable downward spiral for those who are affected. These impressions help to perpetuate stigmatizing attitudes against mental conditions and discriminatory practices against mental patients.

Findings of the landmark psychiatric epidemiological study of Stirling County in Nova Scotia, Canada, are described in a classic book entitled My Name is Legion [1]. This biblical quote [2] is used by many writers and, as used in the Stirling County study, it conveys the large number of those affected. Years after this study and on observing how mental patients are treated, managed or disposed of in many countries, it is obvious that their numbers do not change their plight in society. Despite their numbers, mental patients do not count politically, they are powerless. It is the thrust of this chapter that whereas attitudes such as stigma might be endured, discrimination has to be counteracted; rights have to be fought for.

This chapter contains a historical overview on matters of stigma and includes a review of theoretical elements that lie at the foundations of stigma as a social construct and its negative impacts on patients and their families as well as a dissection of common elements of programmes aimed at combating the stigma of mental illness. The chapter also contains a review on the matter of discrimination which is considered to be the most pernicious aspect of stigma as it impacts on the political and civil rights of mental patients.

Historical elements

Stigma, a tattoo or brand in Greek (from the verb stizein), was a distinguishing mark burned or cut into the flesh of slaves or criminals by the Ancient Greeks so that others would know