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0521549434 - Reducing the Stigma of Mental Illness: A Report from a Global Programme of the World Psychiatric Association

Norman Sartorius and Hugh Schulze

Frontmatter

[More information](#)

Reducing the Stigma of Mental Illness

The stigma attached to mental illness is the main obstacle to better mental health care and better quality of life for people who have the illness, for their families, for their communities and for health service staff who deal with psychiatric disorders. Stigma is pernicious and there are indications that, despite advances of psychiatry and medicine, it continues to grow and have more and often terrible consequences for patients and families.

In 1996, the WPA began an international programme to fight the stigma and discrimination associated with schizophrenia. The 'Open the Doors' programme has been implemented since then in more than 20 countries and has involved about 200 different anti-stigma interventions.

This book details the results of these international efforts and provides recommendations and guidance for those seeking to join this initiative or to start similar efforts for dispelling stigma and discrimination.

Norman Sartorius is one of the most prominent and influential psychiatrists of his generation. He has served as Director of the Division of Mental Health at the World Health Organization, and subsequently as President of the World Psychiatric Association. He is a member of the Council of the World Psychiatric Association and of the Expert Advisory Panel of the World Health Organization. He is an honorary professor of the University of London, a professor at the Universities of Zagreb and Prague and has held or holds professorial appointments at the Department of Psychiatry of the University of Geneva and at several other universities in Europe, the USA and China; he is a senior associate of the Faculty of the Johns Hopkins School of Public Health in Baltimore. He has written over 300 scientific papers and has authored, co-authored or edited more than 40 books.

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and

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CAMBRIDGE UNIVERSITY PRESS
Cambridge, New York, Melbourne, Madrid, Cape Town, Singapore, São Paulo

CAMBRIDGE UNIVERSITY PRESS
The Edinburgh Building, Cambridge CB2 2RU, UK

Published in the United States of America by Cambridge University Press, New York

www.cambridge.org
Information on this title: www.cambridge.org/9780521549431

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First published 2005

Printed in the United Kingdom at the University Press, Cambridge

A record for this book is available from the British Library

ISBN-13: 978 0 521 54943 1 paperback
ISBN-10: 0 521 54943 4 paperback

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Contents

	<i>Preface</i>	<i>page</i>	xi
	<i>Introduction</i>		xiii
	<i>Structure of this Book</i>		xix
	<i>Participants in the Programme</i>		xxi
	<i>Acknowledgements</i>		xxv
1	Developing the Programme		1
	What conceptual framework should the programme adopt?		2
	The vicious cycle of stigmatization		2
	Focus on schizophrenia or on mental illness in general?		6
	Who should carry out the programme on country level?		7
	How should the activities of the programme be selected?		7
	What administrative structure should the programme have?		8
	How long should the programme last?		9
	What relationship should there be with other efforts dealing with problems of stigma and discrimination?		10
	How should the programme be evaluated?		10
	References		12
	Phase I Calgary, Alberta, Canada		13
2	The Canadian Pilot Site		15
	Calgary, Alberta		15
	Health care professionals		18
	Emergency room professionals		18
	Medical students, senior health care policy-makers and general health professionals		19
	Teenagers: students in grades 9 and 11		21
	The Teens Talking 2 Teens Competition		23

Cambridge University Press

0521549434 - Reducing the Stigma of Mental Illness: A Report from a Global Programme of the World Psychiatric Association

Norman Sartorius and Hugh Schulze

Frontmatter

[More information](#)

vi	Contents	
	Community Change Agents and opinion leaders	24
	Who <i>is</i> the general public?	27
	Conclusion	29
	Bibliography – Canada	31
	Phase II	33
3	Spain	35
	Working from the inside out	37
	Interventions for individuals living with schizophrenia and their families	38
	Health care institutions	38
	An approach to the public	39
	Results	40
	Bibliography – Spain	41
4	Austria	42
	Establishing a benchmark	43
	Targeting journalists	43
	Educating high school students	44
	Broadening the audience	44
	Mental health services	45
	Conclusions	45
	Bibliography – Austria	46
	Phase III	47
5	Germany	49
	Düsseldorf	51
	Interventions undertaken since 2000	52
	The first ‘Anti-stigma Prize’ in Germany	52
	Anti-stigma Training Modules	52
	Competence Centre for Destigmatization of People with Schizophrenia	53
	Hamburg	53
	Itzehoe-Steinburg and Kiel	54
	Leipzig	54
	Interventions based upon Focus Group results: secondary school students	55
	Adult education	56
	Media	56

vii	Contents	
	Munich	56
	Conclusion	58
	References – Germany	59
	Bibliography – Germany	59
6	Italy	62
	Research	63
	Stigma and high school students	63
	Stigma and journalists	64
	Working with employers and their employees	65
	Conclusion	67
	References – Italy	68
	Bibliography – Italy	68
7	Greece	70
	A unique national opportunity	71
	Mental health professionals	72
	Working with the media	72
	Expanding the volunteer network	73
	Stigma and the arts	74
	Support materials for communication	75
	Stigma and high school students	76
	Individuals living with schizophrenia and families	76
	Local networking and awareness	77
	Conclusion	77
	Bibliography – Greece	78
8	United States	80
	Employers	81
	Criminal justice system	82
	Media and the general public	84
	High school students: reaching beyond schools	84
	Conclusion	85
	Bibliography – United States	86
9	Poland	88
	Putting the structure in place	88
	Assessing needs	89
	A national perspective	90
	A non-governmental organization dedicated to schizophrenia	90
	Teachers and students	91

Cambridge University Press

0521549434 - Reducing the Stigma of Mental Illness: A Report from a Global Programme of the World Psychiatric Association

Norman Sartorius and Hugh Schulze

Frontmatter

[More information](#)

viii	Contents	
	Employers	91
	Church and clergy	91
	A Day of Solidarity	92
	Conclusion	93
	Bibliography – Poland	94
10	Japan	95
	Follow-up research on effectiveness	96
	Study 1: Japanese psychiatrists	96
	Study 2: Individuals diagnosed with schizophrenia	97
	Study 3: Family members	97
	Study 4: General public/college students	97
	Study 5: Psychiatric professionals in universities	98
	Guidelines for the future	98
	Working in the community	99
	Tokachi	100
	Sendai	100
	Okayama	101
	Moving forward	102
	References – Japan	103
	Bibliography – Japan	103
	Phase IV	105
11	Slovakia	107
	Starting in Michalovce	107
	Changing, not fighting, the system	109
	Working with and through the media	109
	Conclusion	110
	References – Slovakia	111
12	Turkey	112
	Building a programme and a non-governmental organization	113
	General practitioners	113
	Working with the general public	114
	Consumer and family members	115
	High school students and teachers	115
	Conclusion	116
	Bibliography – Turkey	116

ix	Contents	
13	Brazil	117
	Establishing the programme	117
	Targeting two communities	118
	Objectives, target audiences and research	119
	Educational initiatives	120
	Building a coalition	120
	Cultural activities	121
	Conclusion	121
	Bibliography – Brazil	122
14	Egypt	123
	Research	123
	Primary care physicians	124
	Individuals living with schizophrenia and family members	124
	Journalists	124
	Interventions	124
	Working with medical students	125
	Secondary school students	125
	Broadening the programme	125
	Bibliography – Egypt	126
15	Morocco	128
	Research	128
	Family members and individuals living with schizophrenia	128
	Medical professionals	129
	Interventions	129
	On-going focus on medical professionals	131
	Conclusion	131
	Bibliography – Morocco	132
16	United Kingdom	133
	Phase One	133
	Implementing workshops with police officers	134
	Implementing workshops in schools	134
	Findings and recommendations	135
	Phase Two	136
	Conclusion	136
	Bibliography – United Kingdom	137

x	Contents	
17	Working in Partnership – Australia	139
	A wealth of information resources	139
	In collaboration with the media	140
	Award-winning efforts	140
18	Chile, India and Romania	142
	Chile	142
	Interventions in the psychiatric community	143
	Consumers and family members	144
	Reference – Chile	144
	Bibliography – Chile	144
	India	145
	The importance of family support	145
	New initiatives	146
	Educational initiatives	147
	Working with the National Service Scheme	147
	Bibliography – India	148
	Romania	149
	References – Romania	151
19	Conclusions and Recommendations	152
	Structure and flexibility	153
	Target groups	155
	A question of media	162
	Development of messages	166
	Recommendations about principles of programme development	169
	Reference	171
	<i>Afterword</i>	172
	<i>Appendix I</i>	175
	<i>Appendix II</i>	215
	<i>Appendix III</i>	223
	<i>Appendix IV</i>	229
	<i>Index</i>	234

Preface

The Second World War is now becoming a dim memory for all but those who lived it. Among them, those who were not soldiers by profession, civilians caught in the maelstrom of misery, death, terror, starvation and suffering also remember it with particular clarity.

In that war, my mother, a pediatrician, joined the partisans in Yugoslavia and took me along. Although this has been more than half a century ago and I was only 8-year old I still remember the time we spent with the resistance movement with extraordinary clarity: the years immediately before and after have long receded into vague landscapes of time. Among the memories of the war is one of the nasty winter of 1943 when I had an experience that gained in significance over the years.

We had completed many hours of enforced march and had come to a road that we had had to cross: it was well guarded and it was necessary to wait for a period between the enemy patrols to get to the other side. Everyone had to remain absolutely quiet. We held that position for hours waiting for the signal to proceed. It was there that I saw a cortege, a carriage with six white horses, with attendants dressed in eighteenth century costumes and finery pass by on the protected road. It was quite beautiful and I remember how extremely clear it seemed to me. I heard the sound of the hoofs and muted voices of the attendants. The carriage was moving slowly and once it passed another came along. This hallucination lasted for what seemed a long time. When I pointed to the sight and described it to others they looked at me puzzled and ordered me to stop talking about it.

Over the past few decades a number of new findings contributed to our knowledge about schizophrenia. Some of these relate to morphological changes of the brain observable by the increasingly powerful investigative techniques. Others relate to the nature of the schizophrenic experience, to the importance of maintaining the patients' self-esteem for the process of recovery and to the positive role that families can play in helping the patient if properly trained.

And yet, for all the advances that have been made by the neurosciences, by the social and behavioural sciences, by studies of treatment and by public health investigations the mystery of the brain–mind barrier seems as impenetrable as it always was. Jim van Os and others demonstrated that typical symptoms of

Cambridge University Press

0521549434 - Reducing the Stigma of Mental Illness: A Report from a Global Programme of the World Psychiatric Association

Norman Sartorius and Hugh Schulze

Frontmatter

[More information](#)**xii****Preface**

psychosis appear in people who never consulted a doctor for it with a surprisingly high frequency (Verdoux and Os, 2002): why some of these experiences appear and vanish while others stay or keep coming back and occupy one's mind is still unclear. Why did I see the cortege with white horses when no one else saw it and why did this type of experience never come back even though there were many other situations in which I was exhausted, hungry, sleepy and frightened? And what would have happened to me had I been brought to a hospital, kept there for observation and maybe given some treatment? Could the label of being kept for observation in a mental institution have changed my subsequent schooling, social relationships and working life?

The level of our ignorance is such that it is safe to predict that much more time is necessary before we learn enough about schizophrenia to be able to prevent it. We can however provide care to people who suffer from schizophrenia and know what could enhance the probability that our treatment will be successful and that patients will find their place in society. We know what obstacles stand in the way of recovery and rehabilitation. Among these obstacles undoubtedly the most serious and difficult is the stigmatization of mental illness and of all those in contact with it – the sufferers, their families, the medications used for treatment, the institutions in which treatment is provided, staff in mental health institutions and even the sites on which they are located.

This book is about stigma and ways of fighting it. It reports on what we and the other participants in the WPA Global Programme against Stigma and Discrimination because of Schizophrenia have learned from it. It also contains our thoughts about ways of intensifying the programme and making it an essential part of health services, equivalent in importance to training staff about ways to treat diseases.

We hope that this volume will make readers aware of the nature of stigmatization of mental illness in different cultures and of the consequences of stigma and discrimination for all concerned. We also hope that it will make readers eager to join those who fight these because they are awesome obstacles to progress not only for mental health programmes but also for progress towards the creation of a civil society.

Norman Sartorius
Geneva, Switzerland, 2005

REFERENCE

Verdoux, H. and van Os, J. (2002). Psychotic symptoms in non-clinical populations and the continuum of psychosis. *Schizophrenia Research*, 54(1–2), 59–65.

Introduction

The stigma attached to mental illness and all that is related to it – patients who suffer from mental disorders, their families, psychiatric institutions, psychotropic medications – is the main obstacle to better mental health care and better quality of life of people who have the illness, of their families, of their communities and of health service staff that deals with psychiatric disorders. It is a basic component of the negative discrimination that people with mental illness experience every day. It blocks access to facilities and options that, in principle at least, have been created to help people impaired by mental illness. Stigma is pernicious and what is worse there are indications that despite advances of psychiatry and medicine stigma continues to grow and has more and more often terrible consequences for patients and families.

The stigma associated with schizophrenia is particularly harsh. A person diagnosed with the illness will be seen by most of those around him or her as dangerous, lazy, incompetent at work, unable to be a family member that fulfills his or her social obligations. Different fears and prejudicial judgments may be in the foreground of stigma in different cultural settings: what is common is that the negative opinion will stay stable even after all the symptoms of the disease have disappeared and after it has been possible to show that the individual concerned can work and fulfill his social roles at least as well as his fellow citizens.

That stigma exists and that it is pernicious is gradually becoming accepted (Link *et al.*, 1992). This growth of awareness is however only rarely accompanied by the commitment or at least willingness to do something about diminishing stigma and its consequences.

The reasons given for inaction by mental health workers (and by others who should be concerned with stigma) are varied. Some say that they are too busy, others that individuals cannot change stigmatization. Still others state that stigma linked to mental illness is not very different from the stigma attached to other illnesses and therefore only a comprehensive programme which is beyond their reach can make sense.

The different voices of stigma and discrimination

During the course of the programme in interviews, in focus groups and more public forums, those living with the illness and their families have described many different ways stigma and discrimination is manifested:

From India: 'My parents support me but we can't tell any of our neighbors. It would hurt my sister's chances of being married.'

From Canada: 'If I apply for the job and tell them I have schizophrenia, I won't be hired. If I don't tell them and they find out, or I suffer a relapse later, I will be fired.'

From Japan: 'Women with an illness like this will be kept at home to do domestic chores, while we men are sent out of the house.'

From the United Kingdom: '[T]he only way I found out the doctors had diagnosed me with schizophrenia was because I managed to read it upside down on my medical notes! No one had told me and finding out that way was very frightening. I felt very alone.'

From the United States: 'The doctors left me waiting in the emergency room, fighting my delusions for six hours; they said other people's problems were more serious than mine.'

The Global Programme of the World Psychiatric Association

In 1996, the World Psychiatric Association undertook a programme to address the stigma and discrimination because of schizophrenia. At a meeting in Geneva, Switzerland, 38 psychiatrists from more than 20 countries and representatives from consumer groups discussed ways to address the barriers to proper treatment, the difficulties with reintegration, and how best to address the human rights of those living with the illness and of their families.

Collectively, the group agreed to three guiding principles for the programme:

- to survey individuals living with the illness and their family members about the experience of stigma and discrimination, and where possible encourage their active participation;
- to encourage the participation of individuals throughout the community whether in health care, government or private enterprise – everyone was welcome;
- to ensure this was a long-term effort, rather than a brief campaign.

To start the programme it was necessary to develop guidelines and manuals. Initially, these would be drafts which would be improved upon in the course of time. To produce those materials the Steering Committee established four other groups:

xv The Global Programme of the World Psychiatric Association

The *Treatment Committee* was charged with compiling the latest information on the illness and the variety of treatment options available. For the first year, the head of this group was the Italian psychiatrist, Mario Maj. In 1997, Wolfgang Fleishhacker of Austria stepped into that role.

The *Reintegration Committee*, chaired by Julian Leff of the UK, was to examine results of research done on reintegrating individuals back in society.

The *Stigma Committee*, the largest of the four groups, surveyed the manifestations of stigma and discrimination because of schizophrenia in different cultures and countries. Richard Warner from the US directed the efforts of that group.

Finally, while the programme's Steering Committee oversaw the interworking of the groups, the *Review Committee* would review the documents produced by the groups.

After reviewing the evidence and relevant facts, the groups produced a single volume on schizophrenia. The volume was written in the style of an encyclopedia entry, easily readable and based on evidence. The volume was annotated with remarks indicating sections particularly relevant to fighting stigma. This volume was meant to provide a central compendium of the latest scientific information on schizophrenia for the media and programme participants. This volume has been translated into Spanish, Polish, Italian and Japanese. In Spain, it has been published as a book.

The groups next produced a step-by-step guide for implementing an anti-stigma programme. The group understood that most of the implementers of the programme in individual countries would have had little or no experience in addressing public awareness or changing public opinion and wanted to provide guidance on social marketing efforts. That volume was drafted by Dr Sartorius and Dr Hugh Schulze with the help of Dr Warner, and reviewed by the Steering Committee and other experts, such as communication professionals. It is designed to assist psychiatrists and other mental health professionals in assembling a Local Action Group, setting measurable goals and objectives, and identifying key target groups for the programme. The guide includes suggestions on how to hold a press conference, write a press release, and numerous other practical tips. After years of its use, the volume has been further developed through the creation of a Manual with practical suggestions based upon the experiences of the programme and use of the volume.

The steps outlined in that initial volume take Local Action Groups roughly 12 to 18 months to implement – from initial planning meetings to full implementation. Over the years, a number of general principles have emerged that have applied in all countries:

- The programme's goals should be based upon information obtained from patients and their families in the culture in which they live.

- The programme should be directed at particular, defined target groups.
- The programme should be undertaken first in areas in which success is likely in the short term to encourage all participants.
- The programme should include active participants willing to stay with the programme for at least 2 years.
- The Local Action Group should develop a plan of action and invite leading personalities in the country to join the programme's support group.
- The programme will place all of its experience and funding at the disposal of other programmes participating in the global effort, and in turn rely upon their resources when and where necessary.
- When identifying select target groups it is important to have an individual from that particular target group on your team – not only can they provide insights on the best way to address their peers, but recommendations on individuals and groups you may be unaware of.
- For national programs, a group composed of representatives from the different cities or regions is important to ensuring coordination between the groups and amortizing costs overall.
- In general, the more targeted the intervention – in terms of messages and media directed to identifiable individuals or a group – the more effective the effort will be. (We will see examples of this in the Canadian Pilot Study.)

The volume also contained practical suggestions such as the creation of a project log, establishment of regular meeting times and other suggestions for maintaining group cohesion. Examples from both volumes are listed in the appendices of this book.

Since that first meeting, more than 20 countries have undertaken nearly 200 anti-stigma interventions. As we will see, these interventions were directed towards well-defined target groups in an effort to address different parts of the vicious cycles that lead to discrimination and prejudice.

The WPA and Local Action Groups in different countries have published journal articles and reports on the on-going efforts around the world. They have also made presentations at major scientific meetings, conferences and congresses. This book is intended to gather the latest data from all of these efforts and provide insights into how each initiative was developed in a particular country through the cooperation of men and women from a wide variety of backgrounds.

What sets this programme apart from other anti-stigma initiatives is both its international nature – whereby groups in different countries were able to share best practices – and the collaborative nature of the Local Action Groups. Following guidelines set out by the WPA Global Programme and refined in other countries, these groups bring together psychiatrists and other mental health professionals,

Cambridge University Press

0521549434 - Reducing the Stigma of Mental Illness: A Report from a Global Programme of the World Psychiatric Association

Norman Sartorius and Hugh Schulze

Frontmatter

[More information](#)

xvii The Global Programme of the World Psychiatric Association

journalists, politicians, schoolteachers, and perhaps most notably, those living with schizophrenia and their family members as well.

The First International Conference on the Stigma and Discrimination because of Schizophrenia was held in Leipzig, Germany in 2001. In 2002, further findings were presented at the WPA Congress in Yokohama, Japan, a logical consequence of the fact that the Global Programme against Stigma is one of the five Institutional Programmes of the WPA. A Second International Conference was held in Kingston, Ontario in Canada in 2003. It is expected that further conferences dealing with the work against stigma and its consequences will take place and that they will allow an exchange of experience at the same time as an encouragement to those participating in the programme and others that will join them.

Structure of this Book

The opening chapter provides an overview of the challenge and methodologies used to fight stigma and discrimination. The following chapters provide country-specific reports on interventions undertaken following the WPA guidelines. These have been organized more or less chronologically in four phases. Phase I, which involved the first use of Volumes I and II of the programme materials, was undertaken in 1997 in Calgary, Canada. Phase II was an extension of the programme to Spain and Austria. Phase III included other European countries such as Germany. Phase IV was programme implementation in other countries.

Each chapter concludes with a list of articles relevant to the anti-stigma efforts in that country. The final chapter includes a list of recommendations and cautions relevant in undertaking such a programme. In Appendix I, the reader will find Volume I of the programme – a step-by-step guide to planning and implementation. Appendix II contains sample pages from Volume II, which contains information on the diagnosis and treatment of schizophrenia, along with a section devoted to the stigma and discrimination associated with the illness. We have also included the instruments for surveys of knowledge and attitudes that were used in the Calgary Pilot Study in Alberta, Canada.

Additional information is available at the programme web site:

www.openthedoors.com

Those interested in starting a programme against stigma should contact:

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Please note that those who join the WPA network will be expected to share the data that they obtain in their work with other participating sites and to follow the guidelines of the programme. In turn they will be given access to all of the sites' materials and will be kept informed about the development of the programme.

Participants in the Programme

This programme was developed by experts from many countries, non-government organizations, associations of patients and their families, as well as government representatives.

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Cambridge University Press

0521549434 - Reducing the Stigma of Mental Illness: A Report from a Global Programme of the World Psychiatric Association

Norman Sartorius and Hugh Schulze

Frontmatter

[More information](#)**xxii** **Participants in the programme****Stigma Committee**

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W. Wolfgang Fleischhacker (Austria)

Julian Leff (United Kingdom)

Richard Warner (United States)

Chairpersons and Advisors of Local Action Groups

Each chapter of this book is dedicated to a different initiative in a different country. At the end of each country report, we will list many of those who have helped make those programmes a success. Here, we wish to acknowledge those heads of sites

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0521549434 - Reducing the Stigma of Mental Illness: A Report from a Global Programme of the World Psychiatric Association

Norman Sartorius and Hugh Schulze

Frontmatter

[More information](#)**xxiii** **Participants in the programme**

instrumental in bringing the results to this book. Contact information for individuals and Local Action Groups are given at the end of appropriate chapters. (Like the chapters themselves, the countries are listed in chronological order roughly corresponding to when the initiatives were begun.)

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0521549434 - Reducing the Stigma of Mental Illness: A Report from a Global Programme of the World Psychiatric Association

Norman Sartorius and Hugh Schulze

Frontmatter

[More information](#)

Acknowledgements

This programme would not have been possible without the generous support of many people living with schizophrenia and their families in more than 20 countries around the world, including the family associations that support them. The programme has also been supported by medical and psychiatric institutions, and other agencies many of whom are listed in the appropriate country reports.

We would also like to thank Eli Lilly and Company who have generously supported both the international effort and local initiatives in some countries.

The authors would also like to thank Josette Mamboury in Geneva, Switzerland and Melissa Woods in Chicago, United States for their invaluable assistance in this programme over the years.