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0521615364 - Social Inclusion of People with Mental Illness
Julian Leff and Richard Warner
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Social Inclusion of People with Mental Illness

People with serious mental illness no longer spend years of their lives in psychiatric institutions. In developed countries, there has been a major shift in the focus of care from hospitals into the community. However, whilst it means those with mental illness are not confined, it does not guarantee they will be fully integrated into their communities. The barriers to full citizenship are partly due to the disabilities produced by their illnesses and partly by stigmatising and discriminatory attitudes of the public. This book analyses the causes of these barriers and suggests ways of dismantling them. The book is constructed in two parts, the first relates to social inclusion and the second to occupational inclusion. Throughout, the text is annotated with quotes from consumers, to illustrate their experience of the issues discussed. The innovations outlined are described in sufficient detail for the reader to implement them in their own practice.

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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/9780521615365

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First published 2006

Printed in the United Kingdom at the University Press, Cambridge

A catalogue record for this publication is available from the British Library

Library of Congress Cataloguing in Publication data
Leff, Julian P.
The social inclusion of people with mental illness/Julian Leff,
Richard Warner.
p. cm.
Includes bibliographical references and index.
ISBN-13: 978-0-521-61536-5 (paperback)
ISBN-10: 0-521-61536-4 (paperback)
1. Mental illness. 2. Mental illness – Social aspects. I. Warner,
Richard, 1943– . II. Title.
[DNLM: 1. Mental Disorders. 2. Socioeconomic Factors. 3. Social
Isolation – psychology. WM 31 L493s 2006]
RC454 . L374 2006
362.196' 89dc22 2006008745

ISBN-13 978-0-521-61536-5 paperback
ISBN-10 0-521-61536-4 paperback

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Preface

This is a tale of two systems – the systems of care for people with mental illness in Britain and the USA. Although both the authors are British-trained, one (JL) has practised social and community psychiatry in the UK and the other (RW) in the USA. We have both, however, had ample opportunity to visit the service systems in these two countries and in many others around the world. This exposure to different systems of care has allowed us to present quite a broad range of experiences and models to the reader, but, here and there, it may have introduced a note of confusion.

In Britain, for example, the current term for someone who has experienced an episode of mental illness and has received mental health services is a 'service-user' or 'user'. In the USA, the term is 'consumer'. After struggling with this for a while, we gave up and left you, the reader, to sort it out. Just remember: service-user = user = consumer.

More complicated is the fact that the systems in which we have worked in Britain and the USA developed quite differently after the Second World War, and so the models of treatment and rehabilitation that we have helped to develop were designed to respond to different problems. This is an important lesson in itself. The treatment approaches and models that we describe in this book did not happen in a vacuum – they are responses to specific conditions. An anti-stigma programme in Philadelphia, for example, may need to focus on the police force, because that is the first point of contact for many acutely disturbed people with mental illness in that city. In Glasgow, the same effort might best be expended on family doctors. Similarly, service managers will decide what programme innovation is needed most urgently based on what is the biggest perceived problem, be it the 'revolving-door patient' who relapses several times a year and is repeatedly admitted to hospital, or the person whose symptoms of mental illness are in good remission but whose life is empty and meaningless. Because the context is so important, we will describe here some of the differences between the mental health treatment systems in Britain and the USA in recent

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decades, because these differences influenced the direction that we both took in our work.

Something of a revolution in the treatment of people with serious mental illness was taking place in post-war northern Europe, even before antipsychotic drugs were introduced in 1954 – a revolution that went unnoticed in the USA until it was well under way. British psychiatrists transformed the psychiatric hospitals by abolishing the use of restraints and seclusion, mixing the genders, unlocking the doors and establishing power-sharing therapeutic communities in which staff and patients shared in decision-making about the hospital environment and its management. Group homes were developed for long-hospitalised patients to live in the community. In so doing, northern European psychiatrists stole a march on the rest of the world in developing treatment environments that fostered recovery from psychosis and an early return to community living. This progress slowed down for a while in Britain after 1970, when the Seebohm Report led to a statutory division between funding for community support and treatment services.

While dramatic changes were taking place in post-war northern Europe, most of the US asylums remained backward and repressive. This provided the moral and philosophical basis for a massive deinstitutionalisation movement that was launched in the USA in the late 1950s. The movement was politically driven, however, by the introduction of the Medicaid health insurance programme, which divided the cost of community care for people with mental illness 50/50 between the state and federal governments, in contrast to state hospital care, which continued to rest entirely on the shoulders of the state government. Most of the discharged state hospital patients ended up in substandard conditions in boarding homes and nursing homes, a situation that was soon to be recognised as a national scandal. The development of a network of community mental health centres after 1965, which often focused efforts on people with lesser disorders, did little initially to help the plight of these ex-hospital patients.

So, in the 1970s, while there were still many patients in long-term hospital care in Britain, in the USA there were huge numbers of 'revolving-door patients' with very little in the way of community care or supportive services. The US services tackled their primary challenge by developing assertive community treatment services to prevent relapse and hospital admission. Many British services, on the other hand, were still dealing with patients who had been in hospital for decades and were suffering the consequences – symptoms such as agitation, passivity, pacing and incontinence. The best British services developed residential treatment settings to move long-hospitalised patients into more domestic living environments in the community. When pressure mounted in the 1980s to close more British asylums, many of the treatment services expanded their network

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of residential settings and developed home services provided by community nurses. As the hospital closures advanced, often these measures were inadequate to meet the demands created by the new young clients with serious mental illnesses. Many acute hospitals and community treatment teams found themselves overstretched. British services began to examine US and Australian models that had been developed in order to address these problems, especially assertive community treatment and crisis intervention.

At the time of writing, the two systems are more similar than they have been for decades. Both systems have developed methods to prevent relapse and to get along with few acute psychiatric hospital beds. Both are now grappling with the issues that we deal with in this book. How do we help people with psychosis who are living in the community become *citizens* of that community? How do we help them find valued social roles and to escape poverty, victimisation and, sometimes, prison incarceration? How do we help the community to see these people as fully entitled, fully human community members? Recovery from mental illness is about more than just getting rid of the symptoms and staying out of hospital. It is about regaining a sense of identity, belonging and meaning in life.

To illustrate this process of recovery, we collaborated with two researchers from Brisbane, Vaidyanathan Kalyanasundaram and Barbara Tooth, who are experienced in interviewing people with serious mental illness about aspects of their lives that allowed them to achieve mastery of their mental illnesses. With another interviewer, who has mental illness herself, they interviewed 20 people in Boulder, Colorado, all of whom had overcome the obstacles presented by psychotic illness to lead full and productive lives. The comments of these consumers on coping strategies, work, stigma, speaking out, obstacles and optimism are introduced in the relevant sections throughout this book. We are most grateful for their contributions.

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