Partnerships for Mental Health

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Editors

Partnerships for Mental Health

Narratives of Community and Academic Collaboration

Springer

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To Eric and our family

—Laura

To Amelia, Ethan, and Heidi: you are the wind in my sails and you inspire me to try to make the world a better place for all.

—Daryn

To my wife, Tara, whom I met in a community collaborative meeting. Through both your work and personal interactions, you continue to daily teach me the true meaning of community partnership.

—Steve

To the schools in the San Francisco Bay Area that we have been privileged to walk alongside of and grow with. A special thanks to Malathy, Aanand, Amrit, and Sanjan for their loving support and for tolerating the many late-night arrivals after community meetings.

—Shashank

Foreword

Partnerships Between Academic Medical Centers and Community-Based Organizations Enhance the Mission and Impact of Each

To address the complexity of modern challenges and opportunities, partnerships are increasingly important in a variety of different disciplines. This book presents meaningful and moving examples of partnerships between members of academic medical centers (AMCs) (e.g., faculty, students, and staff) and community-based organizations (e.g., clients, patients, leaders, volunteers, and workers). The examples described in these chapters provide tangible evidence of the positive impact that these partnerships have had, and continue to have, on the health and welfare of individuals and communities.

I am particularly pleased and grateful that many of the community partnerships described in this book have been developed by Stanford faculty. I also appreciate the role of Dr. Laura Weiss Roberts, Chairman of the Department of Psychiatry and Behavioral Sciences at Stanford University School of Medicine, and her departmental colleagues, Drs. Daryn Reicherter, Steven Adelsheim, and Shashank Joshi, in encouraging these partnerships and in editing this book.

AMCs have had a critically important role in virtually all major biomedical advances over the past century. The groundbreaking report of Abraham Flexner in 1910 [1] identified the need for a scientifically based curriculum in medical schools. The implementation of recommendations from the Flexner report led to the formation of AMCs with tripartite and interrelated missions of patient care, research, and teaching. Diagnosis and treatment of diseases were advanced, innovations abounded, and patient care improved—particularly for patients with acute illnesses who were treated within the four walls of a hospital. Communities have certainly benefitted from the Flexner revolution, but only more recently have AMCs viewed outreach to communities and partnerships with community-based organizations as an integral part of their broad mission to improve human health.

As we look to the future, community partnerships, such as those described in this book, will be of increasing importance to the core mission of AMCs, which is evolving to focus on a broader view of health as something more than just medical care for acute illnesses. This mission is evolving for at least three reasons. First, many scientific opportunities compel us to look at the mission of an AMC as being broader than the diagnosis and treatment of disease. We now have within our grasp the opportunity to make major advances in the prediction and prevention of disease, thereby adding a new dimension to the scope of engagement and impact of AMCs. Second, integrated and coordinated approaches over long periods of time are required to provide effective care for patients with multiple medical problems. This need compels us to broaden our scope of focus to include effective care for patients with chronic diseases in addition to our traditional focus on acute diseases. Third, as expressed in a number of ways, society now expects all of us involved in the delivery of health care in America to be much more focused on value (e.g., improved outcomes at lower cost).

Community partnerships will be essential for success in each of these areas. Collaboration with community partners is needed to promote well-being and stop disease before it starts—from providing local screenings to ensuring vaccine compliance. As more and more individuals cope with chronic disease, community initiatives increasingly provide programs that support healthy habits, like smoking cessation and exercise—areas often forgotten in the provision of medical care. Finally, as we work toward improving value in health care, greater coordination across medical and social and community service providers will play a key role in sustaining long-term health in a cost-effective manner.

Another factor that is pushing AMCs toward increasing community partnerships is an increased awareness of the social determinants of health—the conditions in which we are born, live, and work—and the prominent and yet often unacknowledged role these conditions play in our well-being. Abraham Flexner himself recognized the importance of social factors, asserting that physicians have the duty "to promote social conditions that conduce to physical well-being" [1, p. 68]. The function of a physician, he noted more than a century ago, "is fast becoming social and preventive, rather than individual and curative" [1, p. 26].

The programs and activities described in each of the chapters of this book provide compelling examples of passionate commitment, unfailing optimism, and steadfast persistence. We learn about Lawrence McGlynn's personal journey as a boy growing up in the San Francisco Bay Area during the early years of the HIV epidemic [2]. McGlynn's perspectives evolve during his transitions to medical school, residency in psychiatry, and appointment as a faculty member. His desire to improve the lives of those with HIV and methamphetamine addiction and to bring the epidemic into check led him to provide care to patients at the Partners in AIDS Care and Education (PACE) Clinic in San Jose and the Positive Care Clinic at Stanford. In addition to the care he provides as a psychiatrist, McGlynn has been involved in educating health care workers and community members about the linkage between methamphetamine addiction and HIV. His work has also included studies and interventions aimed at reducing methamphetamine use.

Suzanne Walker and Victor Carrion [3] describe the effects of chronic stress and trauma on the health of children and youth in a San Francisco community. A dose–response relationship has been demonstrated between adverse childhood experiences (including physical neglect and abuse, emotional neglect and abuse, sexual abuse, and substance abuse in the household) and adult risk of chronic disease. Walker, Carrion, and their colleagues developed the Center for Youth Wellness with collocated pediatric medical and mental health services as a part of a federally qualified heath center in Bayview Hunters Point (a residential neighborhood of San Francisco that has experienced high rates of poverty, community violence, and adverse environmental exposure). They found that 12 % of the children in this community were affected by four or more adverse childhood experiences, and 51 % of these children were identified as having learning and behavioral problems. Evidence-based therapies have been developed through partnerships that include teachers, pediatricians, psychiatrists, dentists, and nutritionists.

On the international front, the chapter of the book written by Jayne Fleming and Daryn Reicherter [4] describes how a group of physicians and human rights lawyers came together to send a legal-medical delegation to Haiti a month after the devastating magnitude 7.0 earthquake in 2010. Reicherter, a psychiatrist and recognized expert in cross-cultural trauma, led the medical team. Fleming, a pro bono attorney at Reed Smith LLP, led the legal team. They and their colleagues went to Haiti to understand the human rights situation and to identify individuals who might qualify for evacuation due to extraordinary circumstances, such as medical conditions that could not be treated in Haiti. Thirty-seven candidates for humanitarian parole were identified during their first visit, all of whom were victims of rape and suffered from posttraumatic stress disorder.

This first visit to Haiti led to an enduring commitment, and volunteers with the Haiti Humanitarian Project have since made about 30 more trips to the country, working closely not only with community groups but also with the United Nations High Commissioner for Refugees. When faced with financial and logistical challenges on the ground, the team has persevered and developed innovative solutions. They have used cutting-edge telehealth technology to help assess whether or not people met criteria for refugee status. By late 2014, the group had succeeded in permanently resettling 52 Haitian women and children in the United States and Canada.

The partnerships described in this book provide an exciting glimpse into the transformative effects of partnerships between communities and the faculty, students, and staff at AMCs. I have focused on three of the narratives, but each story provides unique understanding of how collaboration can bring about positive change.

Such improvement is urgently needed, as there remains much room for improvement on the health care landscape. The United States has some of the best hospitals in the world, and American patients have earlier access to cutting-edge drugs and treatments and generally shorter waiting times to see physicians. But on broad measures of health outcomes like infant mortality and life expectancy, the United States ranks near the bottom among the countries belonging to the Organization for Economic Coordination and Development. Moreover, improvement on these types of indicators is slower in the United States than in most other nations.

AMCs have an important role in addressing these shortcomings. To realize our potential, we need to expand our mission beyond *care* to include *health*—and not just for individuals but also for communities. By partnering with community-based organizations, AMCs are increasingly focusing on prevention, chronic disease, health care value, the social determinants of health, and other significant factors that contribute to human health and well-being on a broad scale.

We live in a time of enormous potential for biomedical discovery and improvements in human health. Collaboration between community and academic partners will play a critically important role in realizing this potential. The collaborations highlighted in this book are inspired examples of what can be accomplished.

Lloyd B. Minor, M.D.

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Preface

I lived in New Mexico 10 years before I wore a western-style belt, so deep was my intention to not appear other than what I was—a kid from Chicago who loved the sky, the mountains, the high desert, and the green chile of New Mexico.

I trained and worked at the medical school, and each year I marveled at the young physicians who would come and, within days of their arrival, don tall cowboy hats and boots, denim of a particular cut, and silver and turquoise. These men and women would come for adventure, enticed by what was novel to them in this large, sparsely and diversely populated frontier. These young healers came to New Mexico promising to learn and to dedicate their efforts to a place rich with poverty, need, and risk. Some of these young physicians stayed (usually trading their initial Southwest costume for a more subtle bolo tie or earrings). And yet, many of these same men and women would leave. They were unhappy with all that was unfamiliar to them. They were exhausted by the demands of a rural, relentlessly resource-poor place. Commitments made to individuals and to the communities of New Mexico no longer held, and, the sense of promise was no longer felt.

A second, more positive observation from this formative time in the Southwest relates to the ingenuity that arises in situations of overwhelming need and few resources. A great example is a program developed decades ago by a child psychiatrist from the university who was working in a frontier community in which many adolescent girls were becoming pregnant and dropping out of school. These young mothers and their children were experiencing tremendous mental and physical health challenges. Most were not doing well at all. Their futures were becoming diminished and the entire community was affected. Efforts by teachers and local leaders to "educate" young people about birth control and pregnancy over many years were essentially ineffective. Working with the community, the psychiatrist came up with an idea: to develop a toddler care program and, in this carefully supervised setting, to employ young teenage girls as the caregivers. Through one initiative, many of the older adolescent mothers in the community were able to return to

school, bringing far more salutary outcomes to their families. But another effect was felt among the adolescent girls working in the toddler program: seeing how difficult it was to take care of little kids, the teenagers made considerable efforts to avoid becoming pregnant. The pattern was disrupted.

Another great example of necessity as the "mother of invention" was a collaboration over nearly two decades that has brought together state, county, and university partners to address the overwhelming needs of elders who reside in remote areas throughout New Mexico and have serious mental illnesses, such as depression, anxiety, late-life psychosis, and dementia. Few resources exist for this greatly burdened special population of New Mexico. New Mexico is the fifth-largest state in the United States, with 0.6 % of the country's population, so most of the state qualifies as truly frontier (i.e., fewer than 6 people per square mile), and it has few clinics, hospitals, and health professionals. New Mexico also is economically distressed, currently ranked 48 out of 50 states with respect to fiscal health, with one in five individuals living below the poverty line. And New Mexico, like other rural states, has an overrepresentation of children, elders, and disabled individuals. Alone, the state could never do enough. The counties could never do enough. The university could never do enough. Together, however, the three partners could bring different elements from which an effective program could be, and was, built. The state contributed resources, novel solutions for reimbursing home-based care, and networking with a broader system; the counties contributed local clinic and generalist clinician efforts; and the university contributed subspecialty expertise, clinical trainees, continuing education, and respite support. In this program, a circuit-riding faculty physician traveled the state—working side-by-side with community-based colleagues, performing clinic, home, and video visits with rural elders and their families, and training physicians interested in rural health care.

My work in academic-community partnering has evolved since my early days in New Mexico and, even before, in urban underserved communities of Chicago. I have had the privilege in my academic work to engage with individuals from all walks of life and most places throughout the world. In my work at Stanford Medicine, we now have activities and initiatives in our neighborhood and across the globe. Several of the stories of these partnerships are told in this book. Other partnership narratives shared here are those of my friends, and of the friends of my friends.

Partnerships for Mental Health: Narratives of Community and Academic Collaboration is a text that follows from an earlier work that Christiane Brems, Ph.D., Mark Johnson, Ph.D., and I created with many remarkable colleagues. That book, *Community-Based Participatory Research for Improved Mental Healthcare: A Manual for Clinicians and Researchers*, was published in 2013 (also by Springer Science+Business Media). The manual laid the foundation for this collection, which has a greater focus on partnerships as experienced by those who create them.

This next book richly tells the stories of collaboration. The narrative voice of each chapter derives from the people who tell their story. Authors of this book are immigrants, survivors of torture, mental health experts, urban people, rural people, teachers, doctors, attorneys, students, and international leaders. Their stories matter. These authors provide emotionally powerful tales that will, I believe, move, affect,

and encourage those who encounter them in this book. Stories are influential. This collection of narratives is inspired by these individuals, who believe that collaboration can bring authentic mutualism, promise-keeping, and innovation to address the hardest problems we face as a world community.

Stanford, CA, USA Laura Weiss Roberts, M.D., M.A.

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Introduction

The giant pine tree grows from a tiny seedling.
A tower nine stories high starts with a single brick.
A journey of a thousand miles begins with a single step.

Lao Tzu

If you want to walk fast, walk alone.
If you want to walk far, walk together.

Russian proverb

Beginning with a Single Step

Mental disorders represent the second-leading cause of disease burden in the world. Only infectious diseases surpass neuropsychiatric, addiction, and related conditions in human suffering, as measured by years of life lost due to early death and severe disability. Affected are people living in cities, in rural areas, in economically established countries, and in economically emerging countries. Affected are people of all ages, both genders, in minority and ethnically distinct communities, in majority communities, and in all strata of society. In seeking to lessen the burden of mental disorders, the obstacles are many: insufficient resources, insufficient expertise, insufficient infrastructure. And then there is stigma. Stigma is pervasive—worsening the suffering experienced by individuals with mental disorders, heightening the barriers in seeking care, and interfering with the creation of adequate systems of care.

Addressing mental health concerns throughout the world is truly a very hard problem. Very hard problems of this nature matter a great deal, and they require innovation and collaboration to resolve. This book is about the stories of innovation and collaboration occurring between community and academic partners who have

undertaken among the very hardest of problems—the care of veterans with ravaging posttraumatic stress disorder; the care of homeless individuals with HIV, addiction, and mental illness; the care of caregivers for Hispanic family members with Alzheimer's disease; the prevention of illness in impoverished vulnerable youth; and the rescue of profoundly mentally ill earthquake survivors. This book also tells the story of identity formation of early-career physicians with a calling to work with distinct populations for whom suffering and stigma are immense. This book also tells the stories of the special bonds that develop and are strengthened between community members and academic colleagues and, ultimately, between friends.

With these narratives, we invite the reader to see how partnerships emerge around a specific, very hard problem and how efforts toward a solution unfold. These narratives offer perspectives on partnerships, documenting the process of working together, reflecting the creativity and fellowship of collaboration, and displaying the different architectures of effective community-academic partnerships. Partnerships between community-based and academic collaborators are intended to bring value in the present, bringing resources and services to make a difference in real time. Reflecting on the process and results of partnerships clarify which approaches may be replicated or adapted to help others elsewhere, making a difference in the future.

Our aim in developing this collection is thus to illustrate and inspire collaboration in order to bring about better health outcomes for people affected by mental health issues in communities throughout the world. Each journey has its beginning. We invite you to join with us in taking the single step of this book's journey.

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