



Mental Illness and Your Town

37 Ways for
Communities
to Help and Heal

Larry Hayes

Praise for *Mental Illness and Your Town*

“With a father's wit and a reporter's well-honed writing skills, Larry Hayes uses his family's story to offer practical suggestions about how communities can help persons with mental illnesses recover and thrive. This is a wonderful blueprint that spells out ways to change lives and help persons seldom seen or heard.”

—Pete Earley, author, *CRAZY: A Father's Search Through America's Mental Health Madness*.

“Larry Hayes—with his background as a journalist, advocate, and parent—understands the challenges that communities face in understanding mental illness. This book outlines the opportunities—and proven steps—we all can take to help ‘get this illness out of the shadows and into broad daylight.’ Larry helped make my city a much healthier place because of his work on mental illness—his book can help do the same for other communities.”

—Paul Helmke, President, *Brady Center/Campaign to Prevent Gun Violence*, Former Mayor of Fort Wayne, IN

“Larry Hayes demonstrates in this book a very rare gift that he has, the ability to reduce complex social problems to simple terms. In addition, he fills the book with practical solutions and ways to reduce the sometimes debilitating effects of mental illness. These will help victims and communities alike to address this reality, that ‘We only help a fraction of those who need help.’”

—James C. Howell, Ph.D.,
juvenile justice researcher

“Like me, Hayes has a history of major depression he has overcome. He is open about this, and about his son’s suffering from a major mental health problem. But this is not a ‘poor me’ story. Rather, it is one of hope and self-empowerment. Hayes is on a mission: to remove the stigma associated with mental disorders, to lead sufferers and their families to self-respect and justice. In these pages, he shows you how you can do the same in your community.”

—Bob Rich, PhD., author, *Anger and Anxiety: Be in Charge of Your Emotions and Control Phobias*

In *Mental Illness and Your Town*, Larry Hayes uses his considerable experience as an editorial writer and mental health advocate to show communities what they can do to help the cause of mental illness. Frequently using illustrations from his own experience and his family's experience with mental illness, he gives realistic, substantive and effective examples of what helps and what does not help in a myriad of different areas of society, virtually blasting negative stigma away. The sheer number of good ideas in this document makes it a treasure for any mental health advocate or group. Included is a primer on how to be an effective advocate that is a gem in itself. I can't recommend this book too highly.”

—Rev. Barbara F. Meyers, Mental Health Minister,
Mission Peak Unitarian Universalist
Congregation, Fremont, CA

“Larry Hayes provides families with a real self-help manual that is personal and compassionate, yet practical and hands-on. In my years in the field, I have not seen a book like it. It is long overdue and can only come from someone who has been there—in the trenches. Larry certainly has.”

—Stephen C. McCaffrey, President
Mental Health America of Indiana

“I loved reading and learning from this book. I share Larry Hayes’ views that we can win the battle against depression, bipolar, and other related disorders if we succeed in counteracting stigma, disseminating knowledge, and enlisting entire communities in the effort. Long ago, I learned that athletes, performers, and everyday citizens who talk about these conditions in matter-of-fact language and with supportive advice become powerful voices in this struggle. Larry Hayes has provided a roadmap as to how to win this struggle. Working together we will do so.”

—John F. Greden, M.D.
Upjohn Prof. of Psychiatry and Clinical Neurosciences
Exec. Director, Univ. of Michigan Depression Center

“*In Mental Illness and Your Town*, Larry Hayes has chronicled many great ideas on how communities can improve their systems of mental health care. This enlightening book reflects the ‘can do’ attitude which Larry has brought to significant challenges and offers strategies on how to move ahead. Several of the ideas in this book have already been implemented in Fort Wayne, thanks in part to Larry’s inquisitive and relentless passion to make things better.” —Paul Wilson, CEO
Park Center, the Mental Health Center, Fort Wayne, IN

“Mental illness is a contentious topic mired in prejudice, superstition, and ignorance. Stigmatized, patients and their families retreat into a fortress of denial and shame. Communities, small and large, and even the medical profession, turn a blind, embarrassed eye and pretend to go on about their business with equanimity.

Unlike the overwhelming majority of tomes concerned with this issue, "Mental Illness and Your Town" is not verbose or condescending. It is a "how-to" manual for would-be activists and it provides hundreds of tips and reams of advice on communal coping with mental illness. In terms of "talent, time, and treasure", this slender guide provides detailed, down-to-earth, action plans tailored to specific audiences: individual volunteers; the Church; the media; hospitals; and many more.

What can one do about mental illness? A lot, it turns out; open a suicide hot line; administer self-tests; distribute cell phones; organize outings; open clubhouses and depression centers; and much more besides. By confining itself to the practical and eminently doable, the book counters our feelings of helplessness and resignation in the face of these ‘cancers of the mind’.

My only mild criticism is that the author, probably owing to personal experience, tends to concentrate on mood-disorders (and, particularly depression). Yet, there are hundreds of other mental health dysfunctions out there. This *vade mecum* will serve them equally well.”

Sam Vaknin, PhD,
author of *Malignant Self-love: Narcissism Revisited*

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**37 Ways for
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to Help and Heal**

Larry Hayes

Mental Illness and Your Town: 37 Ways for Communities to Help and Heal

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*To those who struggle daily
with the challenges of mental illness.*

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About the Cover

On June 20th, 2007, several hundred people from the Fort Wayne community on the Carriage House campus to celebrate the opening of Chad's House, a place for persons from the area to stay when they're training in this highly successful rehabilitation program. Photo provided courtesy of Burke Gallmeister.

Introduction

I should know.

More than twenty years ago, I stood at the bedside of my teenage son as he hovered between life and death in the Parkview Hospital ER. He'd taken an overdose of a powerful antidepressant. Thank goodness he survived. But all his adult life he's battled mental illness. Because of my own experience years ago, I have some idea what he goes through every day.

When John was a small boy, just after my father's death from cancer, I fell into a deep depression myself. I had a six-week stay in the hospital and 12 shock treatments. That time proved to be a hiatus from teaching and family life. It might well have prevented me from taking my own life. Released from the hospital, I joined a therapy group. That helped me reconnect with other people. It was only when I quit teaching school, however, that my depression finally lifted. Through it all, I learned a lot about the shortcomings in a community's response to mental illness. I'm more persuaded than ever that we can do more to help those who suffer find their way back into the mainstream. We can do more to help them find a life of meaning, a life of joy. That's the message of this book for every community.

In 1973, I joined *The Journal Gazette*, Fort Wayne's morning newspaper, to write editorials and columns. I used that platform to advocate on behalf of persons with a mental illness. For background, I drew on my own struggles with depression and my training in abnormal psychology and counseling years before as a divinity student. I interviewed the country's top experts.

I attended conferences. I joined a family support group, a chapter of NAMI, the National Alliance on Mental Illness. State and national advocacy groups honored my writing. I played a role in launching major reforms. I saw our police department adopt a model for intervening when a person with a mental illness got into a crisis. I helped start our county's Suicide Prevention Council. I proposed to the chancellor of Indiana University Purdue University Fort Wayne that he create an institute for behavior studies. That's now a department at the university. I wrote editorials that boosted the opening of the Carriage House, a rehabilitation center modeled after the famous Fountain House in New York City.

So I should know about mental illness. Perhaps the most important thing I know is this. The disability reaches into every neighborhood, every business, every school and more families than you'd imagine. Indeed, our immediate family isn't so exceptional. I just have to go back a generation or two to uncover mental illness on both sides. I've found severe depression, schizophrenia, bipolar disorder, even suicides. Beyond my own family, I've encountered numerous other cases. A former police chief in our city has a mentally ill brother. A judge I know, now in our state appeals court, had a grandmother who had committed suicide. My college roommate's elder son suffers from bipolar disorder. A former secretary of my wife has a mentally ill son.

We tend to think of it as a private, family matter. As a rule, the patient and their families suffer behind closed doors. It's more than that. Mental illness is a serious public health issue. I'm not referring just to the random, inexplicable act of violence that a patient

might commit. The disability takes a high toll in lost work time, wages, health care costs and public assistance. Most of all, how we treat persons with a mental illness ultimately stands as a test for how much we care about each other.

Lots of folks don't get the help they need. I've often interviewed agency directors, psychiatrists, psychologists and social workers. I've spoken with family doctors. I'm friends with the parents, the sisters and brothers. Just about all these people often feel frustrated, helpless. They yearn to make a difference.

Here's my answer. Let's take mental illness out of the ERs, out of the psychiatric wards, out of the doctors' offices, out of the group homes, out of the homes of the families whose loved one's mind is out of whack. Let's get this illness out of the shadows and into broad daylight. For the sake of our neighbors, friends, families, co-workers and children, let's engage the entire community.

This book proposes practical ways a community can respond. It's not technical. I leave it to others to decide what all mental and emotional problems to include under "mental illness." I'm excluding no one in your community from playing a helping role. The tragedy that has befallen people with this pernicious condition is not their fault. They're wrestling daily with these demons of their mind. Let's see to it they don't wrestle alone.

First things first.

You should approach the subject of mental illness with a great deal of humility. To treat these various disorders, you are, after all, tinkering with human

nature, a matter not to be taken lightly. If the labels have changed through the centuries, the phenomenon has cropped up everywhere. Lincoln's depression was melancholy. Freud's patient suffered from conversion hysteria. In some quarters, people still think the person who suffers is possessed by a demon.

Like the labels, the treatments have varied, from the barbaric that amounted to torture to the benign but useless. If we haven't inflicted physical pain, we've inflicted much emotional distress. We've shunned, isolated and raised false hopes. It's not only those diagnosed with a mental illness who could use fixing. It's the rest of us, too.

I know a lot of families who have changed their ideas, adjusted their lives through struggling with a loved one's illness. They've grown up. They've become more caring, more understanding people. They've come to accept the limits of their ability to fix a child or a spouse. That's humility's reward, a sense of peace with the messiness around you.

But this book isn't about passively accepting the suffering that mental illness brings. It's a busy book, chock full of ideas and proposals and *shoulds*. It aims to challenge people to get busy about the business of seeing to it that those who suffer have a better life. As you dip into this book, checking out one chapter, then another in a different section, please don't think I mean to shame anybody. I mean to get your juices flowing, stir some righteous anger, inspire you with possibilities and, above all, persuade you to lend a hand.

Part I

The Faces

Just as mental illness comes in various diagnoses, it shows up in different kinds of people, at different stages of their lives.

1. Start with Mother and Child

Let me say at the outset that mothers don't cause mental illness. That myth was dispelled long ago. But a mother can foster lifelong mental health. That's tough to do when she's depressed.

In the early months, no doubt Wanda was.

I didn't know it as post-partum depression. Was there such a term in 1965? But I can still see her sad face as I'd walk through the door in our Shirley Place apartment in Cincinnati's western hills. She might still be in her housecoat, strawberry blonde hair not combed. She seemed so frustrated, so inadequate with this baby who had no interest in taking naps during the day. The child seemed happy. The mother wasn't.

I tried to be sympathetic. But in truth, I didn't know how to help her.

Wanda, who died in 1997, was my first wife. We'd been married about three years when Robyn was born, in October, 1965. I had dropped my plan to be a minister and was doing student teaching in the morning and early afternoon, then typing freight bills at Mason-Dixon Truck Lines during the evenings. So the two of them, mother and child, were stuck together for much of the day.

It's pretty common for a new mother to get the blues. Most snap out of it within a few weeks. But for others, the blues turns into a major depression. Untreated the depression can last for years. It can become a lifetime of battling the disability, with only periodic remissions.

The story doesn't end there. Most of us can readily grasp this. The relationship between mother and child

is critical to the child's mental health. It's the early bonding. It's the thousand ways a mother communicates to the child that he or she is wanted and loved without condition. Or, in tragic cases, she fails to communicate all that. Maybe the father's love rescues the child, maybe not.

The mother's mental health could be the most precious gift she can give to her child. If you see a baby who appears depressed, listless, it's not a great leap to assume that the mother has been depressed too. She hasn't been able to engage the child.

When the depressed child becomes a toddler, you're apt to find the child cries more easily than other children. That child is the one who develops sleep problems and might act out. In pre-school, that child's problems take on a social nature, disrupting a class and driving the teacher crazy.

As any clinician will tell you, mental health problems in a teenager can often be traced back to early childhood. Fortunately, professionals are beginning to find ways to connect young parents with resources. But reaching everyone who can use the help can be an uphill battle. New mothers may not admit they're depressed. Family members might not pick up on the mother's distress. Or the stigma associated with mental illness blocks out sympathy and understanding.

Outside the family, things aren't much more enlightened. Family doctors aren't well-trained in the pathologies of mental illness. They're especially likely to misdiagnose depression in racial and ethnic minority mothers. Other health care workers face the same limits of knowledge. Further, few persons who work in child care have more than the most cursory under-

standing of mental illness. As for high-school-age babysitters, I hate to guess. I imagine ignorance abounds.

I'd start with the pediatricians. I don't assume that they're as uninformed as the rest of us. But I'd conduct an inventory on how they deal with a new mother's depression. See if they include any material on post-partum depression in the packet they send the mother home with. Meantime, I'd approach the pediatricians. Find out whether they see any shortcomings in their training and get their proposals for addressing those gaps.

To raise awareness for professionals, we're talking about regular workshops on mental illness. The practices of family doctors and some specialists could be greatly enhanced by adding a psychiatric nurse, psychologist or social worker who is experienced in helping children who suffer a mental illness. As a rule, doctors know that many of the physical complaints people bring to them have an underlying mental health problem. Do most doctors know enough to diagnose a mental illness in the case of an infant or toddler? Do they know enough to treat such a child? These are issues any community's advocates in mental health can investigate.

Short of organizing conferences, advocates can invite doctors to put out reading materials on infant and childhood mental health. They can encourage doctors to run videos on mental health instead of the cable news shows on their TV monitors in the waiting rooms. What about after-school training in mental health for parents? What about offering tips on mental health on the back of menus the schools send home

with the kids? And don't assume it's the first time mother who is most at risk. Often, the mother's depression doesn't develop until the third or fourth child. Ask beauty shops to subscribe to parenting magazines. Or barber shops. Be sure to include fathers.

Helping young parents cope pays dividends years into the future. I've interviewed a number of prison officials in charge of young men and women who've become a menace to others. It's as if these officials have memorized some required catechism: "We don't start to fix these people early enough."

Don't misunderstand. Again, I'm not saying that a child's mental health problems can be traced back to a mother's depression. (My daughter, a mother of two teenagers, is a successful teacher and parent.) But even if a child suffers no long-term ill-effects from the mother's depression, the stress on both isn't the best way to begin a lifelong relationship. That stress can only reinforce whatever mischief is in the child's genetic inheritance. Further, let's say the mother got lucky and completely skipped any episode of depression. That fact doesn't completely insulate a young child from a risk of early mental illness.

In recent years, national organizations and a few at the state level have cropped up to offer programs that address mental health in infants and children. Yale's Child Study Center has been a leader. Zero to Three in Washington, D.C., has coached people not to think of the issue in infants and young children as one of a serious mental illness. Most times, we're not even considering medications for treatment anyway. Instead, Zero to Three advises us to think of the issue as one of mental wellness. That's the whole point, isn't it?

Nurture mental wellness in a new mother and she then can nurture it in her child. Mom isn't the culprit. She can be a child's best therapist.

2. Let Them Be Workers

This often is the crown jewel of recovery for persons with a mental illness.

Consider this simple fact. Those who work at least part-time seem to do better with their illness than those who don't work. It can beat therapy. It can beat medications. It ranks right up there close to family love. Surveys have found that most people with the disability do want to work. Contrary to the stereotype, about half of these folk actually hold jobs.

I'm most familiar with the clubhouse model. We know it here in Fort Wayne under the name Carriage House. Like nearly 300 worldwide, our clubhouse is modeled after Fountain House in New York City. This is a highly successful pro-work program I'll describe in detail in Chapter 28.

Despite this and other job programs, persons with a mental illness are employed at only two-thirds of the rate of persons in the general population. That figure could be much better. Trouble is, most programs tend to direct people into low-status jobs: dishwashers, custodians, file clerks. Otherwise talented, often highly educated people not only find such jobs boring but also demeaning. Indeed, one thing we've known for years is that persons whose employment is a match for their schooling are more likely to stay on the job and to better manage their illness. Education is the best predictor of success in a job.

Hurdles to greater participation in employment remain. Since some mental disorders strike a person in his or her teens, they often get to middle-age without ever having held a job long enough to develop a work ethic. They don't understand the dos and don'ts. Even at that, a person can start a job, find it stressful and give up within a few days or a week. The person often assumes the illness tripped them up. That's not necessarily the case. Employers, family members and job coaches should encourage the person to stick it out, at least until the disabled person has learned the job. Fact is, you don't have to be mentally ill to find a new job stressful at first. A new job is likely to be stressful for anybody.

Under the Americans with Disabilities Act, a person with a mental illness doesn't have to disclose his or her medical history. Unfortunately, if that person is discriminated against in the workplace, he or she might not know to invoke the ADA, fearing retaliation.

I'd like to see it become routine for local NAMI chapters and other advocacy groups to man a booth at job fairs. It's a good way to offer sound advice to persons with the disability. It's also a good way to make connections with employers and enlighten them about the valuable work a person with the illness can do for them. Advocates, with the support of mental health services, can institute a job fair of their own.

Community leaders always want to see everyone who is capable of working in some kind of a decent job. If you're a NAMI member or an advocate on your own, you can challenge these leaders to survey employers to discover who welcomes those workers battling a mental illness. Meantime, the community mental health center