

INDIVIDUAL PLACEMENT AND SUPPORT

AN EVIDENCE-BASED APPROACH TO
SUPPORTED EMPLOYMENT

Robert E. Drake

Gary R. Bond

Deborah R. Becker

INDIVIDUAL PLACEMENT AND SUPPORT

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Individual Placement and Support

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*This book is dedicated with deep appreciation to all of the courageous
people who have gained employment through
IPS supported employment.*

*Bob Drake
Gary Bond
Debbie Becker*

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PREFACE

Researchers are fundamentally students, striving to clarify the nature of a problem, to assemble knowledge in a coherent picture, to formulate useful questions, to answer these questions using rigorous scientific methods, and to disseminate new information. After studying employment for people with mental illness for many years, we summarize our journey thus far: where we started, what we currently know about helping people succeed in work, what we are trying to learn now, and where we think the field is headed. By sharing our thinking as well as summarizing research, we hope to stimulate other researchers, for much remains to be done. The book is primarily for the students and researchers who will advance the fields of psychiatric disability and rehabilitation. Others with interests in mental health services research—the process of developing evidence-based interventions, conducting the research, understanding the research findings, and the dissemination of research—are welcome to join the journey.

When we began this effort over 20 years ago, several facts were clear: People with mental illnesses expressed a desire for regular employment but rarely entered the mainstream workforce. Professionals, families, and the public were pessimistic about employment as a legitimate goal. After focusing for centuries on the deficits related to mental illnesses, professionals emphasized all the reasons that people with mental illness could not work. Families feared that work would be too stressful for their relatives, perceiving that symptom remissions were fragile, recognizing that disability insurance and meager benefits were critically important, and accepting that stability was a sufficient goal. The public view of mental illness was fearful and inaccurate, consistently misinformed by the media's attention to horrific but rare anecdotes.

In this rather bleak context, we have endeavored to improve employment prospects for mental health clients because so many expressed the goal of meaningful employment in regular work settings. We listened to people describe what they needed, what they found helpful, and what they found hurtful. We studied successful clients, clinicians, and programs. We gathered expert opinions and used scientific methods to test conflicting ideas. Our journey has challenged conventional wisdom, public prejudice, and dysfunctional policies at every step. This book summarizes our thinking up to 2011.

Before we begin, we want to acknowledge that the book reflects the thinking and work of many people. When Drake and Becker began to study employment in New Hampshire in the 1980s (in 1994 joined by Bond, who had been independently researching vocational services in various psychiatric rehabilitation programs), numerous clients and family members, many of whom prefer to remain anonymous, met with us and described their disappointing and occasionally constructive experiences in the service system when they attempted to find and keep employment. Don Shumway, who got us started, and Jim Musumeci, Tom Fox, and Paul Gorman from the New Hampshire Division of Behavioral Health encouraged us to improve vocational services in New Hampshire and supported our research, as did Bruce Archimbault, Paul Leather, and others from the New Hampshire Division of Vocational Rehabilitation. Jess Turner and Phil Wyzik of West Central Services, and Nick Verven, Ken Snow, Bill Rider, and Ed Bailey of the Mental Health Center of Greater Manchester gave their time and supported our efforts to study employment in natural and planned experiments.

Numerous mental health and rehabilitation professionals with experience and expertise in vocational services met with us, generously gave us advice, and assisted us in defining and studying programs. Among those professionals were Len Stein, Mary Ann Test, Jana Frey, Bill Knoedler, and Deborah Allness from the Program for Assertive Community Treatment in Madison, Wisconsin; Bob Liberman, Jim Mintz, and Chuck Wallace from UCLA; Bill Anthony, Marianne Farkas, Karen Danley, and Sally Rogers from the Boston University Center for Psychiatric Rehabilitation; Morris Bell and Bob Rosenheck from Yale University; Tony Lehman and Howard Goldman from the University of Maryland; Charlie Rapp and Linda Carlson from the University of Kansas; and Paul Wehman from Virginia Commonwealth University.

Over the years, many colleagues and students at Dartmouth have collaborated with us in developing and studying Individual Placement and Support (IPS). We particularly thank Greg McHugo and Haiyi Xie, our constant muses as methodologists and statisticians on all studies. Other valued Dartmouth colleagues over the years have included Hoyt Alverson, Marianne Alverson, Phil Bush, Elizabeth Carpenter-Song, Mike Cohen, Robin Clark, Pat Deegan, Laura Flint, Lindy Fox,

Crystal Glover, Paul Gorman, Will Haslett, David Lynde, Susan McGurk, Matt Merrens, Kim Mueser, Saira Nawaz, Sandy Reese, Michelle Salyers, David Strickler, Karin Swain, Sarah Swanson, Will Torrey, Rob Whitley, Rosemary Wolfe, and Emily Woltmann. Over the years, Bond's graduate students at Indiana University-Purdue University Indianapolis, including Kikuko Campbell, Laura Dietzen, Melody Dilk, Kim Dreher, Lisa Evans, Amanda Jones, Colleen Katuin, Marina Kukla, Alan McGuire, Piper Meyer, Jeff Picone, Sandy Resnick, Angie Rollins, Michelle Salyers, Amanda Taylor, and Kathleen Vogler have also contributed through dissertations, masters theses, publications, and other work to our understanding of vocational services for people with serious mental illness. We are also indebted to our colleagues at Thresholds in Chicago, including Jerry Dincin, Ginnie Fraser, Rochelle Frounfelker, Sheila O'Neill, Sandra Wilkniss, and Tony Zipple, where we have conducted a series of recent IPS studies. Many colleagues and collaborators around the United States and in other countries have helped with IPS studies. Among these colleagues are Susan Azrin, Tom Burns, Nicole Clevenger, Angelo Fioritti, Lisa Dixon, Bill Frey, Shirley Glynn, Howard Goldman, Mustafa Karakas, Eoin Killackey, Eric Latimer, Janice Machado, Steve Marder, John McGrew, Harry Michon, Roline Milfort, Alec Miller, Keith Nuechterlein, Oshie Oshima, Ernest Quimby, Jarnee Riley, Miles Rinaldi, David Salkever, Peggy Swarbrick, Rich Toscano, and Jaap van Weeghel. Finally, we are indebted to our funders, the National Institute of Mental Health, the National Institute of Disability and Rehabilitation Research, the Substance Abuse and Mental Health Services Administration, the Social Security Administration, and the Johnson & Johnson Office of Corporate Contributions, especially to our friend and collaborator Rick Martinez, whose support, vision, and encouragement over many years have been invaluable.

Bob Drake, Gary Bond,
and
Debbie Becker

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BACKGROUND AND CONCEPTS

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1

INTRODUCTION

Simply stated, here is the situation we confront as clients, family members, professionals, researchers, advocates, and policy makers: Most people with serious mental illnesses (about 70%) want to work. Like others, they want the responsibility, status, dignity, regular activity, income, challenge, social connections, opportunity to contribute, satisfaction, and all of the other things that employment provides. Despite these interests, only 10–15% of people with serious psychiatric illnesses in community treatment programs in the United States are competitively employed (Bertram & Howard, 2006; Henry, 1990; Lindamer et al., 2003; Pandiani & Leno, 2011; Rosenheck et al., 2006; Salkever et al., 2007). Rates are even lower, typically less than 5%, in follow-up surveys of people discharged from psychiatric hospitals (Farkas, Rogers, & Thurer, 1987; Honkonen, Stengård, Virtanen, & Salokangas, 2007). National and international surveys of community samples, which include respondents with less serious disorders, have reported employment rates of 20%–25% for people with schizophrenia and related disorders (Marwaha et al., 2007; Mechanic, Bilder, & McAlpine, 2002). Traditional vocational programs of many kinds have demonstrated little success in improving these dismal rates of employment (Bond, 1992; Bond, Drake, Becker, & Mueser, 1999).

In the 1980s supported employment began to emerge in many forms as an intervention for people with psychiatric disabilities. Supported employment for people with psychiatric disabilities has been standardized and studied as the Individual Placement and Support (IPS) model. As we review below, the research on IPS has been remarkably robust and consistent. Most people who participate in IPS find satisfying employment, typically improving over time as they gain experience and become steady workers. Currently, IPS helps approximately two-thirds of

participants in clinical trials to achieve competitive employment. We are learning more about how to help the other third.

Nevertheless, after nearly two decades, the spread of IPS in the United States has been slow. One recent survey (SAMHSA, 2009) estimated that only 2% of people with serious mental illness receive any form of supported employment—a far cry from the 70% who want to work!

Furthermore, new challenges have emerged. Health care financing continues to emphasize medications rather than psychosocial services and rehabilitation supports. More people with mental illnesses receive psychotropic medications, but people with the most serious psychiatric illnesses get fewer and fewer needed psychosocial services (Frank & Glied, 2006). Partly as a result of these trends, people with serious mental illnesses are increasingly shunted into the criminal justice system, thereby complicating their employment goals (Fisher et al., 2006; Teplin, Abram, & McClelland, 1996; Tschoopp, Perkins, Hart-Katuin, Born, & Holt, 2007). In addition, the national recession and high rates of local unemployment have created new barriers to employment for people with disabilities (Fogg, Harrington, & McMahon, 2010; Kaye, 2010).

What can researchers do to address these problems and to move the field ahead? In this book we invite all stakeholders to think with us about psychiatric rehabilitation, examining the challenge from different perspectives, considering the state of current research, and planning for the future. People with mental illnesses themselves have become an important force—in politics, advocacy, clinical services, peer supports, and research. Similarly, family members, professional advocates, policy makers, and other stakeholders have important roles to play in reforming mental health care in the United States. All stakeholders need reliable and valid data to make good decisions. Producing such data is the fundamental job of researchers.

After more than two decades working on these issues, we are eager to share how we have considered these problems, what we have learned about doing research in the process, and what may be helpful in the future. For those of you who are students, we encourage you to become researchers who make a difference in people's lives. Publishing papers that have no impact is easy; pursuing promotions and the trappings of academia can be false goals; and following the money from industry or consulting can be even more dangerous. But producing data that actually help people with mental illness to improve their lives should be our goal in mental health services research. We have a boundless opportunity: little is known, services are poor, many people need our help, and our work is directly practical.

DEFINITIONS

Let's begin with a few definitions to make sure we are speaking the same language. We will endeavor throughout to use everyday English and to avoid mental health jargon, but clarifying a few basic terms is necessary.

Supported employment is a generic term with a federal definition but without specific guidelines (Federal Register, 1992). IPS is the only evidence-based approach to supported employment for people with serious mental illnesses. IPS has evolved over two decades and continues to evolve as the evidence develops. The standard for change is the evidence base for improving vocational outcomes.

Serious mental illness is often used synonymously with the term severe and persistent mental illness. It denotes people whose lives are derailed by mental health problems for significant periods of time—people who have significant impairments in major life roles, such as self-care, employment, and intimate relationships (Bhugra, 2006; U.S. Department of Health and Human Services, 1999). Adults with serious mental illnesses usually have psychotic disorders, such as schizophrenia, or severe forms of mood disorders, such as bipolar disorder or chronic depression. Although some people rebound from these illnesses quickly and avoid long-term impairments, many others are affected for years. Because definitions and counts of mental illness and impairment vary (Schinnar, Rothbard, Kanter, & Jung, 1990), exact numbers are uncertain. But most government reports, across many countries, estimate that 3% – 5% of adults between ages 18 and 65 have a serious mental illness (OECD, 2009). Serious mental disorders have been noted throughout recorded history (Torrey, 2001), are relatively common in all parts of the world, and produce an enormous disease burden (World Health Organization, 2001b). The rates of impairment may differ in less industrialized countries (Harrison et al., 2001), but many individuals nevertheless struggle in relation to culturally defined roles. Serious mental illnesses comprise a major proportion of the global burden of disease (Prince et al., 2007; Wang et al., 2005). Societal costs include health and social care, amplified significantly by the impact of disability on employment status, income, and need for subsidized housing (Saxena, Thornicroft, Knapp, & Whiteford, 2007).

Disability is a status based on personal, environmental, and social factors as well as level of impairment (Bartlett, Lewis, & Thorold, 2006). Illness or injury is only a component. For example, an individual with the impairment of paraplegia might require a wheelchair for mobility but would become disabled only if his or her work, income, health care, housing, transportation, and interpersonal environments created unnecessary barriers. The situation is more complicated for people with mental illnesses because the conditions themselves are often unobservable, are highly stigmatized, tend to fluctuate, and have only a minimal direct relationship to functional status (Institute of Medicine, 2002; World Health Organization, 2001a).

Mental health disability produces individual and societal costs. Individual costs include the pain and suffering related to secondary disablement in addition to the primary illnesses, as well as the impact on the ability to work and earn an income. Societal costs encompass all of the negative effects related to having a large group

of individuals become socially and economically marginalized, often with long-term dependency on services. In the era of long-term institutionalization, these effects were predominantly the costs of running the institutions, whereas today psychiatric disablement impinges on society in more complex ways.

People with serious mental illnesses are people first. They are not diagnoses—they are not schizophrenics, bipolars, or depressives. They are people with a diagnosis or a disorder. The distinction is important. It reminds us all to relate to, help, support, and treat the person, not the diagnosis.

People who use the mental health system are variously referred to as *clients*, *patients*, *consumers*, *survivors*, *users*, and other terms. We use these terms interchangeably, recognizing the validity of common usage.

Recovery is a multifaceted concept—simultaneously an ideology, a movement, a vision, a personal process, a set of principles, a set of standards for care, and a banner of hope (Whitley & Drake, 2010). In psychiatric rehabilitation, we generally use the term to refer to a process in which people with illnesses or disabilities move beyond preoccupation with illness, become hopeful about the future, and pursue their own journeys and goals (Deegan, 1988).

Values are also important—from the perspectives of people with mental disorders, professional caregivers, and society. People with the most serious and disabling mental disorders are experts on their own personal experiences, their own individual aspirations, and their own preferences regarding health outcomes and interventions. Honoring their views and autonomy—often in the form of shared decision making—is a theme we develop throughout this book. Professional caregivers have clearly articulated values (Beauchamp & Childress, 2001), simply stated as respect for the individual (being honest), beneficence (trying to do good), avoiding maleficence (not doing harm), and justice (treating everyone fairly). These are also themes throughout our book. And what about society? Perhaps the clearest statement of societal values in relation to psychiatric rehabilitation is the Americans with Disabilities Act, which states that people with disabling conditions have civil rights and protections in employment and other public settings (Americans with Disabilities Act of 1990). Again, this theme reverberates throughout our book.

THE PRIMARY GOAL: PEOPLE WITH SERIOUS MENTAL ILLNESS WANT TO WORK

Why is this surprising? People with mental illnesses want the same things that the rest of us want: to live freely, to have friends and companions, and to be productive. Evolution and society have selected for these traits because they are consonant with survival, adaptation, and procreation. People with impairments and illnesses are fundamentally human and want to pursue these goals as well.

Freedom and relationships are important aspects of recovery, but this book is about productive activity. People with mental illnesses want to be productive. Early in the course of mental illness, nearly all people want to remain in or return to school or work. The only exception might be a small minority of young people who have been socialized into antisocial lifestyles very early in life, before they develop mental illness. Yet even these misdirected youths typically maintain the hope of returning to legitimate employment (Bourgois, 2003; Robins, 1966). Somewhat more surprising is the fact that the majority of older people with long-term mental disorders still want to work (Twamley, Narvaez, Becker, Bartels, & Jeste, 2008). Surveys of people with serious mental illness typically show rates of expressed interest in employment at about 70% (Frounfelker, Wilkniss, Bond, Drake, & Devitt, 2011; McQuilken et al., 2003; Mueser, Salyers, & Mueser, 2001; Ramsay et al., 2011). This high figure is only surprising because of the pervasive acculturation process that most people with serious mental illnesses have endured: early school or work failures, ubiquitous social stigma, low expectations of professionals, the often lengthy and humiliating process of declaring oneself permanently and totally disabled in order to obtain a poverty-level income and health insurance, and the grinding experience of unemployment, poverty, disenfranchisement, and marginalization. And yet people still want to work! The drive to be productive is human, innate, and almost inextinguishable.

The barriers to employment for people with serious mental illness are legion (Braitman et al., 1995; Cook, 2006; Henry & Lucca, 2004; Rosenheck et al., 2006; Secker, Grove, & Seebohm, 2001; Stuart, 2006). The acculturation process described above is overwhelming (Estroff, Patrick, Zimmer, & Lachicotte, 1997). Imagine spending three years proving to the Social Security Administration that you are permanently disabled in order to get health insurance: getting doctors' reports, signing documents, appealing decisions with even stronger arguments, maybe obtaining a lawyer who advises you to avoid work! It's no wonder that people sometimes believe that they are in fact disabled. Then the threat of losing Social Security benefits and health insurance looms. Clients at every mental health center hear horror stories about losing benefits, being asked to pay back money, and having difficulty getting back on Social Security. Maybe the process would be easier if the rules were clear. But nothing could be further from the reality. Even Social Security employees have difficulty understanding the complex rules, mostly geared to people with physical disabilities and often not easily applied to psychiatric disabilities, and people frequently get conflicting or incorrect information from official sources. In addition to fear of losing benefits, people with serious mental illness face multifarious barriers: lack of education and work history, fear of failure, fear of application forms, employers' bias, society's bias, lack of appropriate clothes, lack of transportation, lack of interviewing skills, low expectations of mental health professionals, rejection by state vocational

rehabilitation agencies, and on and on. The traditional 10–15% employment rate begins to look high in relation to the barriers!

Why do people with serious mental illness want to work in the face of such great odds? Read their stories, talk with them, and listen carefully. Their reasons are diverse, but one motivation is consistent. Like people with other serious illnesses, they strive to conduct their lives in as normal a fashion as possible. People with a highly stigmatized illness like schizophrenia still have a strong desire for normalcy—to pursue a meaningful life, to be part of the community, to avoid being defined by the illness. For reasons of identity, self-esteem, and social confidence, they would prefer to say, “I work at the recreation department” or “I’m an assistant at the nursing home” rather than “I’m unemployed due to mental illness.” In addition, they want the other things that employment provides to everyone: extra income, a structure for the day, social opportunities, a feeling of accomplishment, the chance to contribute to society, and so on. Literally thousands of published recovery stories document the importance of work in overcoming illness and re-establishing a sense of hope and accomplishment (Bailey, 1998; Clevenger, 2008; Rogers, 1995; Steele & Berman, 2001). As Josie Bailey (1998) wrote, “Now that I’m working, I really notice the difference when I get up in the morning and go out. I say to myself, ‘Hey, nobody knows that I have a mental illness. I’m just a person going to work.’ It makes me feel good.”

Longitudinal follow-up studies (10 years or more) confirm that clients perceive the benefits of working (Harding, Brooks, Ashikaga, Strauss, & Breier, 1987). A large proportion in one study reported that working helped them with self-confidence, hopefulness, boredom, loneliness, relationships, physical health, and energy (Salyers, Becker, Drake, Torrey, & Wyzik, 2004). In another study, a large majority reported that they sought mental health care less often while working and that their feelings about life and about themselves were more positive (Becker, Whitley, Bailey, & Drake, 2007). In a third study, many clients reported that steady work helped them to manage anxiety, stress, depression, psychosis, and substance use; and enhanced their moral, material, cognitive, structural, and emotional lives (Strickler, Whitley, Becker, & Drake, 2009).

To summarize, people with mental illness offer several insights that constitute the phenomenological core of IPS research. The reasons that most want to work are similar to what people in the general population report: pursuing normal adult roles, participating fully in society, having something meaningful to do, meeting other people, having more income, and so on. Like others, they want jobs that are competitive, interesting, and challenging, not sheltered jobs and not jobs that are incongruent with their interests and preferences. We know less about people who choose not to work. Young people often have age-appropriate educational goals rather than work goals. Some people consider themselves retired. Others have found niches in the casual labor market, working when they want, avoiding taxes,