Service Delivery for Vulnerable Populations

New Directions in Behavioral Health
Steven A. Estrine, PhD is the founder and President of SAE & Associates. He has over 35 years of experience as a high-level administrator, strategic planner, and program developer in mental health and substance abuse for the most vulnerable, at-risk population across the lifespan. Dr. Estrine has held positions as Director of Adult Psychiatric Services of the New York State Office of Mental Health, Director of Public Sector Psychiatry at New York Presbyterian Hospital, and Director of Program Development at North Shore-Long Island Jewish Health Systems. Estrine's primary interests, experience, and successes are in programs addressing the needs of persons known to the criminal justice system, persons with co-occurring disorders of mental illness and substance use, persons or families who are homeless, veterans, and the application of health literacy to the issue of improving access to health care for special needs populations.

Heidi Arthur, LMSW is Vice President for Program Development and Grant Writing at SAE & Associates. Heidi Arthur has more than 12 years of experience in human services project design, implementation, and administration. At SAE, her work in the last 2 years alone has yielded over $23 million for programs benefiting children and families. Arthur has previously held grants management positions for both the New York City Department of Health and the New York State Office of Mental Health, where she had oversight responsibility for the $40 million children's service component of the post-9/11 Project Liberty program. She has also developed and implemented a community-based outreach program initiative for pregnant and parenting substance abusers.

Robert Hettenbach, MPS is Senior Vice President for Business Development at PSCH in the Greater New York Area. He has over 36 years of experience in health, mental health, and managed care. As a senior administrator within the North Shore/Long Island Jewish Health Care System, Hettenbach helped develop their managed care network, has been the Executive Director of a local community hospital responsible for quality care, finances, and regulatory compliance. Accordingly, he has developed a unique understanding of the integration of behavioral health with primary care, and the impact of mental illness on the management of chronic and acute medical conditions. Hettenbach also directed New York State's Office of Mental Health's New York City Regional Office, with oversight of eight state hospitals, and responsibility for the licensure of all inpatient and outpatient programs and the distribution of millions of dollars in funding for community-based programs serving the seriously mentally ill.

Maria Messina, PhD is a consultant and program evaluator at SAE & Associates. Messina is a medical anthropologist with more than 16 years of experience in public health, specializing in ethnographic and ethno-epidemiological research including HIV risk environments, behaviors, and sero-sorting/sero-disclosure practices among men having sex with men (MSM) in New York City (NYC); crystal methamphetamine use and HIV risk among MSM in five U.S. cities; crack injection practices and health risks among homeless street youth in NYC; risk and protective factors for drug use among youth in the barrios of Caracas, Venezuela; residential therapeutic community drug treatment among male and female homeless or formerly incarcerated adults in the NYC public shelter system and adjudicated and nonadjudicated adolescents in the United States and Canada; and HIV prevention among YMSM and MSM in the House/Ball and Kiki communities. Messina speaks French and Arabic and is a Fulbright scholar and a Social Science Research Council Fellow for her research in North Africa on gender, sexuality, and Islam.
Service Delivery for Vulnerable Populations
*New Directions in Behavioral Health*

Steven A. Estrine, PhD
Robert T. Hettenbach
Heidi Arthur, LMSW
Maria Messina, PhD
Editors
This book is dedicated to the memory of
three extraordinary mentors

Morton Wallach, MD
Robert N. Butler, MD
Myrna Lewis, PhD
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Contributors

Charles Amrhein is the clinical director of the Bronx TASC Mental Health Court Program, and teaches doctoral students in clinical psychology at the John Jay College of Criminal Justice and forensic psychiatry fellows at the Albert Einstein College of Medicine.

Andrea Blanch, PhD has worked in public mental health systems for over 30 years. She is currently the director of the Center for Religious Tolerance, and consults widely on issues of culture, violence and trauma-informed care.

Ann Boughtin, MS/MPA has held executive positions in government and the private sectors, leading major service design initiatives for behavioral health systems of care, as well as managed care operations with a focus on Medicaid and high need individuals.

Susan M. Bowler, PhD has 20 years experience in policy and system development in child, youth and family services in Rhode Island. She is a leader in the Advanced Youth Forum which is seeking to fully integrate economic development, employment support, and clinical/social services to assist the highest risk youth to succeed in the market economy.

Michael Cheng is a child/family psychiatrist at the Children’s Hospital of Eastern Ontario in Ottawa, Canada, as well as an Assistant Professor with the University of Ottawa, and is the cofounder of eMentalHealth.ca, an initiative of the Provincial Centre of Excellence for Child and Youth Mental Health.

Paul Feuerstein, President/CEO of Barrier Free Living, was, over the past 24 years, instrumental in developing the largest domestic violence program in the country for victims with disabilities.

Nina Rose Fischer, LMSW, PhD has 18 years of experience in program development. Her doctoral dissertation is on transitioning and stabilizing high needs youth in child welfare and juvenile justice in the community.
Henrietta Fishman, LCSW is the U.S. Department of Veterans Affairs Network 3 Manager of Residential Treatment and Homeless Veterans Treatment Programs.

Frank Guida, PhD a psychologist who received his degree from the University of Chicago, is a program evaluator for a number of federal and international agencies, including the Substance Abuse and Mental Health Services Administration (SAMHSA), the National Institute on Drug Abuse (NIDA), U.S. Department of Education, U.S. Department of Labor, National Science Foundation, and the Chilean Ministry of Education.

Nancy Hepler, PhD is an independent Behavioral Health Researcher and Evaluator with a long time affiliation with Meharry Medical College in Nashville, Tennessee.

Sel J. Hwahng, PhD is a Visiting Scholar and Adjunct Professor at the Center for the Study of Ethnicity and Race at Columbia University and was Research Investigator on the New York City Transgender Project at National Development and Research Institutes, Inc.

Mohamed Kanu, PhD, MPH is Assistant Professor & Interim Director of the MPH Program at Tennessee State University College of Health Sciences.

Kenneth A. Knapp, PhD is an economist and gerontologist whose research projects have included public policy issues in health & long-term care, housing, and work & retirement.

Edie Mannion, MSW is co-founder and director of the Training and Education Center, a program of the Mental Health Association of Southeastern Pennsylvania.

Charlotte Muller is Professor Emerita of Economics at City University of New York Graduate School (CUNY).

Nora O’Brien-Suric is a gerontologist with over 20 years experience in the field of aging. She is a senior program officer at The John A. Hartford Foundation.
Jill Wolski Ordoñez is the Director of the United Way 2-1-1 and CONTACT Lifeline in Albany, NY, programs of Family and Children’s Service of the Capital Region.

Dick Orndoff, MEd has been an Executive Manager in both the public and private sectors, working in managed care and behavioral health services, where he led corporate operations and product development.

Harvey Rosenthal has over 35 years of experience working to provide or promote public mental health service innovations and legislative and social policies that promote the recovery, rehabilitation, rights and community integration of people with psychiatric disabilities, most notably as executive director of the New York Association of Psychiatric Rehabilitation Services (www.nyaprs.org).

Jan L. Roth, PhD has over 30 years experience in local and state, public and private sectors serving persons with intellectual and developmental disabilities.

Lisa Schmidt is a Clinical Assistant Professor at Drexel University’s Department of Behavioral Health Counseling and has extensive experience as both an educator and provider of psychiatric rehabilitation services.

Sandra A. Smith, MPH, PhD is Director of the Center for Health Literacy Promotion, Seattle, WA and author of the Beginnings Guides curriculum for promoting health literacy in parents.

Phyllis Solomon, PhD is Professor of Social Work, School of Social Policy & Practice and Professor of Social Work in Psychiatry, Center for Mental Health Policy and Services Research, Department of Psychiatry, both at University of Pennsylvania.

Peggy Swarbrick, PhD, OT, CPRP is Director of the Institute for Wellness and Recovery Initiatives, Collaborative Support Programs of New Jersey, and part-time Assistant Clinical Professor for the Department of Psychiatric Rehabilitation at the University of Medicine and Dentistry of New Jersey.

Denise Torres, PhD is a licensed clinical social worker with over 20 years of direct practice, administration, and research experience.
Sam Tsemberis, PhD founded Pathways to Housing, a nationally acclaimed consumer-driven stable housing initiative in 1992 after years working as a member of a psychiatric street outreach team to house New York City’s chronically homeless street population.

Anthony Vavasis, MD is the Clinical Director of Medical Services, and former Clinical Director of the Health Outreach to Teens Program, at Callen-Lorde Community Health Center in New York City.
Foreword
Preface

Service Delivery for Vulnerable Populations: New Directions in Behavioral Health was written with the aim of introducing innovative approaches to program design, service delivery, and evaluation to graduate students in social work, criminal justice, and psychology. We also hoped to provide public sector professionals around the nation with new material with which to address the pressing needs of their vulnerable populations. With an understanding of the overlapping complexity of the issues being addressed and sensitive to the realities that one size does not fit all situations, the editors engaged 33 specialists in behavioral health and allied fields from venues around the nation, with years of experience and a deep breadth of knowledge in their area of expertise. Their task was to offer new strategies, program initiatives, and concepts, as well as to review available research and literature and present a historic overview of their area of expertise.

This book is the result of their efforts. It explores the needs of adults, children, youth, families, and older persons who are coping with mental illness, substance abuse, HIV/AIDS, and those with co-occurring combinations of these disorders, for whom state and local systems by and large have failed. As anyone who has worked in the behavioral health field is all too aware, too often these problems are compounded by the effects of developmental disabilities and/or social problems, such as poverty, homelessness, criminal justice involvement, racism, and cultural barriers.

In this era of increasingly competitive funding, research documents the success of coordinated systems of care that address the multiple morbidities of those vulnerable populations who characteristically encounter numerous barriers to effective mental and physical health care in our historically fragmented system. It is critical that programs offer dynamic approaches, incorporate evidence-based practices, and target the specific, often unique, needs of the people to be served in order to establish credibility and obtain government and private funding. We believe that New Directions in Human Services Delivery answers the need for a broadly focused text that will make a significant contribution to students of behavioral health and the providers, consumers, and key stakeholders within the behavioral health community.

New Directions in Human Services Delivery is organized around nine broad issues. Following are brief reviews of what the reader will find in each category.
Part I—New Directions in the Treatment of Persons With Psychiatric Disabilities begins with a comprehensive review of the evolving definition of the term “serious mental illness” and its impact on health-care policy, program development, and treatment. The concept of recovery and its impact on the consumers’ role in the management of his/her illness and the treatment staff’s knowledge about consumers and their needs are explored. Observations are made of how evidence-based psychosocial strategies and services are transforming how people with psychiatric disabilities are being helped to recover and lead fulfilling lives, including a description of these practices. The chapter concludes with identification of future directions in the development of new funding, services, and approaches.

Part II—New Directions in Services for Children, Youth, and Families addresses the impact of co-occurring needs and the barriers to access to care for children and youth with multiple mental health and/or substance abuse needs that are related to stigma; cultural and developmental factors; and fractured systems, as well as the opportunities for engagement that exist when services are driven by families and youth. The prevalence of children with complex behavioral health needs within the Juvenile Justice and Child Welfare systems is examined. The Systems of Care approach is explained and the Wraparound model is described and illustrated as a best practice guide to individual service delivery for children and youth with multiple needs whose care requires attention from a range of systems.

Part III—New Directions in Services for LGBTQ Individuals provides a chapter devoted to a summary of the special needs of LGBTQ youth, and one relating to LGBTQ adults. Dr. Maria Messina and coauthors describe research reflecting a growing body of evidence that LGBTQ youth have health-care needs that are different from their heterosexual, gender-conforming peers. Authors integrate the resulting consequences of the historical lack of access to appropriate care among LGBTQ youth and the consequences of lack of access among LGBTQ youth to appropriate care. Many of the conclusions proposed in the chapter on sexual minority youth, such as a more comprehensive sexual behavior assessment, improve the health care of all youth, irrespective of identity. In their chapter on adult LGBTQ persons, Messina et al provide a comprehensive overview of behavioral risks and factors in order to determine the most sensitive and effective service delivery strategies for issues such as abuse/victimization, HIV/STIs, behavioral health, substance use, domestic violence, gender transitions, and aging.

Part IV—New Directions in Housing and Homelessness directs its attention to the quintessential victims in American society, where homelessness
often serves as a shorthand for minorities and those suffering from a range of physical and emotional problem. This section focuses on factors that negatively affect the residential stability of three unique target populations—persons with psychiatric disabilities and often a co-occurring substance abuse problem, veterans; and older adults. Dr. Sam Tsemberis, founder of Pathways to Housing, the nationally recognized program for homeless individuals, discusses his concept of the unconditional provision of housing for persons with psychiatric disabilities, without the contingency of treatment participation. Tsemberis and the coauthor explain that residential stability is the *sine qua non* for successful treatment engagement and adherence, and evidence is offered to support the efficacy of this consumer-driven approach to reduction of homelessness among those with psychiatric disabilities. Henrietta Fishman’s chapter on veterans speaks to the causes of homelessness amongst veterans as compared to anon-veteran population; the changing demographic of the veteran homeless population; veterans perceptions of their needs, and how to effectively address the issue of homelessness amongst this cohort. It discusses the “New York experience” as a model for the provision of services to homeless veterans. The final chapter in this section focuses on elements that affect housing security among older persons, the special vulnerability of older women, as well as insights on helping people age in place by integrating mental health interventions with other indicated wraparound services to address issues, such as depression and loneliness, which many older persons attempt to hide. The chapter discusses integration into elder-friendly housing of a full array of ongoing, specific services including assessment by a Certified Social Worker, short- and long-term goal planning and interventions, and referral to medical, psychiatric and specific social service interventions, where indicated, to respond to issues relating to the various iterations of elder abuse, depression, alcoholism, substance abuse, and HIV-AIDS in this population.

Part V—New Directions in Services for Older Adults discusses two complex issues relating to needs of the growing demographic of older adults; behavioral health and elder abuse. Drs. Guida and Estrine address behavioral health and unique substance use issues and medical comorbidities that are faced by persons aged 50 and older, with emphasis on minorities and women. Included are several innovative evidence-based practices. The following chapter relates to the prevalence and various forms of elder abuse, and factors that make older adults particularly vulnerable. The section concludes with a description of an innovative program designed to address the emerging silent social epidemic of elder abuse.
Part VI—New Directions in Services for Refugees examines the impact of trauma on refugee populations. The recent groups of refugees and immigrants, unlike earlier immigrants, are maintaining their cultural identity rather than assimilating completely. These new patterns of assimilation, coupled with frequent traumatic histories of newcomers, are extremely challenging to social services. Nationally recognized expert in refugee trauma, Dr. Andrea Blanch identifies the scope and varied precipitants of trauma experienced by refugee populations, and the role that population-based cultural values, norms, and beliefs play in informing the experience of trauma. Dr. Blanch presents innovative models of trauma treatment for refugee populations, including those derived from the application of current models of trauma treatment and those developed from, and informed by the unique culture and experiences of the refugee population.

Part VII—New Directions in Services for the Disabled explores the related themes of persons with intellectual and developmental disabilities, autistic children, and disabled women who are victims of abuse. The high prevalence of domestic abuse of women with disabilities, historic changes in the treatment of developmentally disabled individuals, and innovative strategies to promote the quality of life are reviewed by experts with years of experience working with developmentally and physically disabled individuals. Dr. Jan Roth discusses the most salient change in care for people with developmental disabilities since the latter third of the 20th century, which is the move from large institutional settings to smaller community residential housing. Paul Feuerstein provides personal experience working with disabled victims of domestic violence. The authors bring a refreshing combination of profound understanding and boots-on-the-ground practicality to these largely ignored Americans.

Part VIII—Critical Considerations in Service Delivery addresses the linked subjects of jail diversion models and that of program evaluations with vulnerable populations. Drs. Amrhein and Barber-Rioja describe in detail both the history underlying the nation’s overreliance on the criminal justice system as the largest provider of psychiatric services and the role of deinstitutionalization, mandatory settings as part of the “war on drugs,” and the movement to create a problem-solving court, as promoting the problem. They highlight the importance of jail diversion strategies and program models embedded in the criminal justice system that provide diversion pathways, such as the mental health court and the TASC model.

Part IX—Emerging Issues and Innovations in Service Delivery is a grand finale, a look at where the field of behavioral health is heading as we discard old systems and ways of thinking and move forward in the 21st century. “New Mental Health Meets New Media” explores innovative
communication strategies, consumer-oriented and new media in origin designed to increase a behavioral health consumer’s access to health care. Explaining how chat rooms, email, video, social networking, message boards, and texting, as well as the Internet offer increased access to services Drs. Jill Ordonez and Michael Cheng describe how these new approaches to communication can help consumers overcome the stigma and shame often associated with traditional behavioral health services. Crisis intervention, information and referral services are cited as adaptable to this new media environment.

In “Health Literacy and Human Service Delivery” Dr. Sandra Smith examines the meaning, measure, and practice of health literacy, while assisting the reader in navigating through conceptual models, research approaches, and intended outcomes, and provide a window into the emerging role of the person centered health care. Teaching the behavioral health consumer functional skills rather than relying on standardized tests of health literacy levels have been shown to improve the person’s ability to have better access to health care, to exert better control over the process, and to improve overall health.

“Consumers as Agents of Systems Transformation” provides a recent historical perspective emerging in the United States beginning in the 1960s of attitudes toward and perceptions of individuals formerly labeled as suffering from, or diagnosed with “mental illness” to the more current trend of neutrally regarding these diverse individuals as “consumers” or simply people who have “psychiatric disabilities.” Executive Director of the New York Association of Psychiatric Rehabilitation Services (NYAPRS), Harvey Rosenthal explains that fundamental to understanding this transformation of using different terms to describe different experiences of behavioral health services are the values and philosophical meanings or paradigm shifts expressed through the movements forging human and patient’s rights. Alternatives to traditional treatments, research on the adoption of recovery from substance misuse to psychiatric disabilities, and self-directed service designs where, among other things, individuals receive support to develop their own wellness goals are also included.

“The Future of Managed Health Care” describes how managed care organizations balance the needs and interests of key stakeholders: payers, members, and providers. The role that each stakeholder plays in the managed care model shapes the operation of the managed care organization that coordinates quality care, manages the health-care benefit, and maintains a network of providers, while monitoring clinical outcomes. This chapter describes the history of managed behavioral health care, particularly Medicaid managed care and provides operational information
regarding the functions of managed care organizations, plan design, reimbursement and payment structures, and emerging trends.

Finally, a word about the terminology used in this text. Although we ma It is important to note that the editors have made every effort to insure that the cultural values, norms, and beliefs of the consumers who are referenced in this book are referred to in a respectful and culturally competent manner. Any perceived shortcoming is unintentional.

Steven A. Estrine, PhD
Robert T. Hettenbach
Heidi Arthur, LMSW
Maria Messina, PhD
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CHAPTER ONE

Defining Severe Persistent Mental Illness

Implications for Knowledge, Needs, and Services

Denise Torres

INTRODUCTION

The persistence of “a tower of Babel” (Bachrach, 1988) regarding the definition of serious mental illness (SMI) despite ongoing attempts to standardize the term reflects its very political and social nature. Although it may appear to be an issue of interest for only researchers and academics, how SMI is defined has real-world impacts on program development and practice. As health and social service delivery incorporates the concept of recovery and related evidence-based practices (EBPs), program design and service delivery will need to fundamentally change. This chapter will review the history of the terms associated with SMI and discuss their implications for knowledge about consumers\(^1\) and their needs. The contentious history of the term will be used to discuss the concept of recovery, resistances to it, and the need to reformulate our understanding of SMI if we are to transform the mental health service delivery system.

\(^1\)Consumer is used as a general term encompassing individuals receiving services within the health and social welfare system recognizing the terminology is fraught with debates and political implications.
COMPETING DEFINITIONS OF SMI

The terms serious mental illness (SMI), serious and persistent mental illness (SPMI), and chronic mental illness (CMI) are frequently used interchangeably, although each comes from a different time period and reflects the ideological forces and economic factors that were at play as much as professional and scientific knowledge. That is, the election of a social designation of consumer groups is informed by different ways of knowing and seeing (Bogdan & Taylor, 1989), which shape and in turn are shaped by policies and practices (Anderson, 1997), with consequences for consumer voice and perceived capacity and culpability (Blau, 2003).

Definitional Sources in the United States

There is an absence of international consensus regarding what constitutes SMI (Ruggeri, Leese, Thornicroft, Bisoffie, & Tansella, 2000) and no comparable World Health Organization (WHO) term exists (Slade, Powell, & Strathdee, 1997). The different ways of knowing and seeing SMI have been informed primarily by the need to create policies and categorize individuals for purposes of service eligibility and access. As Goldman and Grob (2006) note, “mental health policy is shaped by the definition of mental illness associated with the policy” (p. 737). The following is a short discussion of the policy and social contexts relating to commonly used terms.

Chronic Mental Illness

Chronic mental illness (CMI) is one of the earliest terms used to categorize individuals who experience long-term functional impairments due to a mental health disorder. It is ideologically linked to historical debates regarding custodial versus community-based care models and “embodied the view that these people would not improve and required long-term custodial care” (Chinman, Weingarten, Stayner, & Davidson, 2001). During the 1950s, the issue saw a resurgence as mental health consumers recently released from facilities took on the labels of “survivors,” “ex-patients,” and “former inmates” (Campbell, 1992) and aligned with other stigmatized groups to strategically argue for full civil rights (Mizrahi, Lopez-Humphries, & Torres, 2009). The issue was temporarily put to rest by the passage of the Mental Retardation Facilities Act, which funded community mental health centers (CMHCs) that were designed to increase access.
to services (PL-88-164, 1963), and by the legal gains achieved by various constituencies during the civil rights era.

In the mid-70s the issue again took root: In 1977, President Carter established the President’s Commission on Mental Health (henceforth “Commission”) which was charged with “recommending how the mental health needs of the Nation can be met and identifying the relative priority of those needs.” Ultimately, the Commission’s report became the foundation for the Mental Health Systems Act of 1980 (PL 96-398) although most of the provisions would be undone by the Omnibus Reconciliation Act of 1982.

In the same year, the American Psychiatric Association (APA) issued a position statement citing the “deinstitutionalization programs of the past” for the failures of the period, and a strong psychiatric patients’ liberation movement argued against the label “chronic” (Chamberlin & Rogers, 1990).

Legislatively, CMI is addressed in the State Comprehensive Mental Health Services Plan Act of 1986 (PL 99-660), which focused on “establishing and implementing a community-based system of care for chronically mentally ill individuals.” One aim was to correct the lack of mandated coordination between state hospitals and the CMHCs (Grob, 2008). Notably, during this time a surge in homelessness was burdening hospitals and treatment facilities (Neibacher, 1990). Given that many homeless persons had mental disorders, “deinstitutionalization” was assumed to be the cause (Goldman & Morrissey, 1985; Hopper, 1988; Snow, Baker, Anderson, & Martin, 1986) and, by implication, the CMHCs. While the act did not define CMI, it required that states develop definitions and enumerate persons with SMI. Subsequent legislation specifically mandated “replacing references to chronically mentally ill individuals [in PL 99-660] with references to individuals with serious mental illnesses” (PL 101-639, 1990).

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In 1963, Action for Mental Health, a report issued by the Joint Commission on Mental Illness and Health, had been contracted under the Mental Health Study Act of 1955 (Pub. L. 84-182) although it did not fully implement the report’s recommendations (Koyangi, 2007). Grob (2008) asserts this was due to the influence of the NIMH, in particular Dr. Felix, which developed the concept of CMHCs.

Deinstitutionalization is used here as it is commonly understood (i.e., a time-limited exodus) recognizing that the social problems associated with it are derived from various economic, political, and social forces.
Serious and Persistent Mental Illness

The term serious and persistent mental illness (SPMI) was promulgated by the National Institute of Mental Health (NIMH) during its efforts to formulate a consensus definition (Grob, 2008; Schinaar, Rothbard, Kanter, & Jung, 1990). The definition issued in 1987 is the most frequently cited, and defines SPMI as a function of the 3Ds or:

**Diagnosis:** A major mental disorder according to DSM-III-R: a major affective, non-organic psychotic disorder or a disorder that may lead to a chronic disability such as a borderline personality disorder. **Disability:** Severe recurrent disability resulting from mental illness. The disability results in functional limitations in major life activities. Individuals must meet at least two of the following criteria on a continuing or intermittent basis: (1) Is unemployed, is employed in a sheltered setting or supportive work situation, or has markedly limited skills and a poor work history (2) Requires public financial assistance from out-of-hospital maintenance and may be unable to procure such assistance without help (3) Has difficulty in establishing or maintaining a personal social support system (4) Requires help in basic living skills such as hygiene, food preparation, or money management (5) Exhibits inappropriate social behavior which results in intervention by the mental and/or judicial system; **Duration:** Treatment history meets one or both of the following criteria: (1) Has undergone psychiatric treatment more intensive than outpatient care more than once in a lifetime (e.g. crisis response services, alternative home care, partial hospitalization, or inpatient hospitalization) (2) Has experienced an episode of continuous, supportive residential care, other than hospitalization, for a period long enough to have significantly disrupted the normal living situation.

—Slade et al., 1997, p. 178

Preference for this definition derives from its limitation of SPMI to “major Axis I” disorders and more demanding duration and disability criteria.

Serious Mental Illness

In 1993, the term “serious mental illness” became the official federally legislated term through the Alcohol, Drug Abuse, and Mental Health Administration (ADAMHA) Reorganization Act of 1992 (PL102-321). The act restructured the federal behavioral health service delivery system by establishing the Substance Abuse and Mental Health Services Administration (SAMHSA) and, for the first time, requiring an explicit definition of SMI for adults and serious emotional disturbance for children.
IMPLICATIONS OF OPERATIONALIZING SMI

Although the SAMHSA and NIMH definitions share the three criteria of diagnosis, duration, and disability/impairment, there is significant divergence in how these are operationalized. This reflects a consensus regarding the need for the 3Ds and also continued uncertainty over the specific character, relative importance, or the nature of interrelationships among them (Bachrach, 1988; Schinaar et al., 1990; Slade et al., 1997). The lack of resolution to these fundamental differences influences knowledge of SMI and mental health services for individuals with SMIs.

Prevalence

It is difficult to ascertain how many persons in the United States are living with an SMI at a particular point in time. Schinnar, Rothbard, and Kanter (1991) noted that the lack of a single definition prevented a meaningful national estimate derived from state-level data. Compounding this, much of the research and attention has been focused on the disorders themselves rather than on impairment following from these disorders. Understanding how many individuals have a specific diagnosis does not offer much insight into the prevalence of SMI: disorders are frequently mild, remit, or attenuate over the treatment and life course (Kessler, Chiu, Demler, & Walters, 2005, p. 617).

Morbidity and Mortality

On average, public mental health service recipients die 25 years earlier than the general population (Parks et al., 2006). In an early review including over 20 studies, Felker et al. (1996) found that the standardized mortality ratios were more than double that of the general population. Black and colleagues (1985) found that suicide and accidents were significant factors in the higher-than-expected mortality rates. In a 16-state study, suicide accounted for 30% of excess mortality (Parks et al., 2006).

Comorbidity

It has been noted that “rates of disease for the population with SMI exceed those of the non-SMI population in every disease category” (Parks et al., 2006, p. 14). Felker et al. (1996) found that 50% of persons with SMI had a known medical problem, another 35% had an unknown medical problem, and 20% had medical issues that may exacerbate mental disorders.
Frequent comorbid issues include obesity, nicotine dependence, substance dependence, sedentary lifestyle, cardiovascular disease, metabolic syndrome, diabetes, cancer and cerebrovascular diseases, and comorbid mental disorders (Dickerson et al., 2006; Parks, Svendsen, Singer, & Foti, 2006), of which many are related to or have complex interplays with psychiatric medications (Parks et al., 2006).

Comorbidity is related to increased mortality, poorer health status, and greater disability, with each added comorbid mental disorder increasing the odds of a medical disorder being classified as severely impairing (Druss et al., 2007). Individuals with comorbid conditions (both behavioral and health) tend to use more as well as more numerous services, complicating care coordination, which increases the risk of poorer care (Gijsen et al., 2001). In one study, poorer continuity was related to higher hospital costs and lower community costs, and greater continuity was linked to better consumer outcomes (Mitton, Adair, McDougall, & Marcoux, 2005). Hence, case management services that assertively link consumers, such as Assertive Community Treatment (ACT), and that bring intensive and multidisciplinary community-based services to consumers, have repeatedly had positive impacts on service coordination and outcomes for individuals with SMI (Dixon, 2000; Goldman et al., 2002; Gonzalez & Rosenheck, 2002). ACT model enhancement using higher levels of psychiatric nursing care has demonstrated significant improvements in health and community functioning over ACT-as-usual (Kane & Blank, 2004).

Comorbid mental disorders: Kessler and colleagues (2005) found that greater than 40% of 12-month cases were comorbid (Kessler et al., 2005). Affective, anxiety, and psychotic disorders frequently occur in combination. One study found that social phobias were comorbid with major depressive disorder (MDD) in approximately 20% of respondents, were frequently present with other anxiety disorders, and when participants had both an anxiety disorder and social phobia the rate of MDD was 65.2% (Ohayoon & Schatzberg, 2010). Others have found that from 7% to 70% of persons with schizophrenia have comorbid depression, which increases the risk for rehospitalization and suicide (Delahanty et al., 2001). Issues of trauma and posttraumatic stress disorder (PTSD) are of significant concern because comorbidity is present in greater than 80% of diagnosed cases and complicates treatment (Dadic-Hero, Toric, Ruzik, Medved, & Graovac, 2009). For example, individuals having comorbid depression are associated with poorer outcomes than those without PTSD (Quarantin et al., 2009).

Co-occurring disorders (COD): Public mental health facilities in the United States reported that 24% of consumers with SMI also had a substance-related disorder (Lutterman, Berhane, Phelan, Shaw, & Rana,
More than 21% of adults with SMI reported a dependency on alcohol or illegal drugs even as the prevalence of COD may be increasing, especially for specific minority populations (Compton, Kevin, Conway, Stinson, & Grant, 2006). Although the reasons for COD are complex, research indicates that self-medication with substances is common when individuals have PTSD (Leeies, Pagura, Sareen, & Bolton, 2010), mood (Bolton, Robinson, & Sareen, 2009), and other anxiety disorders (Bolton, Cox, Clara, & Sareen, 2006). In fact, an important finding from a number of studies indicates that the onset of a mental disorder frequently precedes substance disorder (CSAT, 2007).

Consumers who do not receive integrated treatment but instead receive segregated or serial services disengage from care, which is associated with an increase in relapse, an increase in symptoms, and poorer health outcomes (Drake, Mueser, Brunette, & McHugo, 2004). Integrated Dual Disorders Treatment (IDDT) demonstrates that services focusing on providing concurrent and integrated treatment improves both mental health functioning and reductions in substance abuse (Drake et al., 2001; Drake, Mueser, Noordsy, Drake, & Fox, 2003). Although it has become clear that concurrent mental health and substance abuse treatment improves outcomes, an analysis of participants in the National Surveys on Drug Use and Health found that 46% of those with COD and 65% of those with multiple substance and multiple mental health conditions did not receive any treatment (Harris & Edlund, 2005). The continued lack of treatment and integrated service reflects the segmentation of addiction and mental health into distinct silos (Horvitz-Lennon, Kilbourne, & Pincus, 2006) as well as an underutilization of EBPs because of providers’ and organizations’ entrenched beliefs and modes of service delivery, resistance from threatened organizational structures, outdated reimbursement rules, lack of provider training, and a dearth of resources (Corrigan et al., 2001; Drake & Bond, 2008; Rogers, Vegare, Baron, & Salzer, 2007).

**Issues of Significance**

Culture, “race,” and ethnicity: The importance of culture, race, and ethnicity—as well as language (IOM, 2009)—in informing the social context of service delivery is underscored by the disparities in access and

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4The initial bracketing of the term recognizes that there is wide debate regarding the social construction of race as a biological category although given the history of oppression it is meaningful as a social category. In the United States, race and ethnicity are
outcomes for individuals of color and socioeconomic groups not only in mental health but also in primary health care (Smedley et al., 2002; USDHHS, 2001). It has been noted that “the sources of these disparities are complex, are rooted in historic and contemporary inequities, and involve many participants at several levels” (Smedley et al., 2002, p. 1).

At the research level, considerations of culture, race, and ethnicity were historically absent from discussions on mental illness. In the 1970s, the works of Kleinman and others brought the issue of culture to the fore, resulting in numerous studies specifically dedicated to understanding mental disorders within a cultural context. Even as progress was being made, Kleinman (1988, p. xi) noted that “The concept of culture is treated in most psychiatric textbooks as unessential to mental illness and psychiatric treatment.” This failure arises, in part, from assumptions that mental illnesses are primarily “brain diseases,” and by extension that SMIs are a product of specific pathologies rather than complex expressions of biological, social, and psychological factors.

Even after the Surgeon General (1999) and Institute of Medicine (Smedley et al., 2002) issued reports documenting differential access and outcomes for persons of color in mental health and physical health, respectively, culture, race, and ethnicity remain “impractical.” Bass, Bolton, and Murray (2007, p. 918) appropriately warn that “the recognition of the effect of culture on the understanding of mental illness cannot be an after-the-fact consideration… Without such knowledge, we will continue to be stuck with the ‘unsure of culture appropriateness’ caveat as a limitation in research.” In 2001 SAMHSA developed cultural competence standards for mental health services with underserved racial ethnic groups, which include African Americans, Hispanics, Native Americans/Alaska Natives, and Asian/Pacific Islanders. Also, the American Association of Community Psychiatrists (2008) issued a position statement on diversity that included “issues of race, ethnicity, gender identity, language, age, country of origin, sexual orientation, religious/spiritual beliefs, social class, and physical disability.” Nevertheless, culture as a concept continues to be poorly defined, remains difficult to operationalize, and research still “relies on an outdated definition of culture,” which views culture as received rather than defined legislatively for political and economic reasons with the Office of Management and Budget (OMB) using five racial and one ethnic category (see IOM, 2009 for discussion).
negotiated through daily routine social interactions (Lopez & Guarnaccia, 2000, p. 573).

At the service level, research continues to find that the differences in general prevalence and overrepresentation among high-needs groups may be a function of access to quality care (Alegria et al., 2008; Cook, McGuire, & Miranda, 2007; Cooper, Beach, Johnson, & Inui, 2005; Wells, Klap, Koike, & Sherbourne, 2001) including differential access to case management (Barrio et al., 2003), medications (Knudsen, Ducharme, & Roman, 2007), and frequently based on the diagnosis that individuals of color are given (Elwy, Ranganathan, & Eisen, 2008; Hatzenbuehler, Alberti, Narrow, & Grant et al., 2008).

At the diagnostic level, within the context of the larger conflict of the definition of SMI, it is important to recognize that the disorders upon which any definition is built are themselves issues of debate and inherently social. The IOM (2009, p. 22) notes:

With depression there is not even a real scientific definition of the focus of the disease—“mood”—and no accurate way to measure how it changes, nor is there a core understanding of how serotonin impacts the brain as a whole to alter mood.

In fact, studies indicate that the diagnostic criteria used may underestimate the rate of depression among African Americans (Coyne & Marcus, 2006) and their exposure to stress (Turner & Avison, 2003). A vital issue is the difference between disorders as disease and illness: The sociologic and anthropologic literature emphasizes that within the Western medical paradigm, disease is viewed as pathology or maladaptation in biologic and psychophysiologic processes, whereas illness is the expression of reactions to disease, distress, and discomfort shaped by personal, interpersonal, and cultural frames (Gaines, 1992; Kleinman, Eisenberg, & Good, 1978). Differences in vantage points are important, given that research on the nature of consumer–physician encounters suggests that consumers anticipate biased, stigmatizing, and/or nonresponsive provider interactions that may reduce help-seeking (Doescher, Saver, Franks, & Fiscella, 2000; Johnson, Roter, Power, & Cooper, 2004; Saha, Arbelaez, & Cooper, 2003; Snowden, 2003).

Beyond the potential of race, ethnicity, and culture to serve as indicators of social disadvantage and systemic oppression (Smedley et al., 2002; USDHHS, 2001), ethnographers, sociologists, and ethnopsychiatrists have underscored that the expression of illness and the socially sanctioned mechanisms for help-seeking will differ (Gaines, 1992; Kleinman, 1988; Kleinman, Eisenberg, & Good, 1978; Lopez & Guarnaccia, 2000). For
example, Alverson and colleagues (2007) identified ethno-cultural differences among Americans of European, African, and Puerto Rican descent in how consumers “en-story” or communicate their experience of illness and disability. Studies have consistently documented the underutilization of mental health services among racial and ethnic “minorities” (Neighbors et al., 2007; USDHSS, 2001; Wang et al., 2005), with a recent study indicating that among African Americans, beliefs related to the natural remission of mental distress may partially explain the lower utilization rates (Anglin, Alberti, Link, & Phelan, 2008).

Family Involvement

Just as treatment has focused on the index condition a consumer might have, it has focused on intrapersonal issues rather than interpersonal relationships. Indeed, families have historically been viewed as problems rather than assets (Fisher, Benson, & Tessler, 1990), with many professionals seeing families as obstacles to progress, and to believing consumers would benefit from being separated from them (Kim & Salyers, 2008), perhaps deriving from strongly held theories of “dysfunctional families” or more sophisticated iterations of the schizophrenic-genic mother/parent. It is not surprising, then, that families frequently perceive they are being blamed for their family member’s illness or treatment trajectory (Fisher et al., 1990).

Research has begun to examine family needs and preferences, and researchers have found that the stigma related to having a member with SMI is a barrier to engagement in treatment despite high levels of unmet need (Drapalski et al., 2008). For example, some researchers have found that the stigma related to medication with Latinos is a significant barrier (Interian, Martinez, Guarnaccia, Vega, & Escobar, 2007). While needs were as complex and unique as the families themselves, researchers underscored respondents’ need for information about the disorder, discussion and engagement in care planning, and advocacy related to services (Drapalski et al., 2008).

As sources of caregiving and instrumental supports, families experience a great deal of burden related to the ill family member (Shankar & Muthuswamy, 2007). This is especially true for communities of color who may have a preference for more communal approaches. For example, the Latino concept of familismo, which emphasizes loyalty to the family, interdependence among family members, and cooperation, encourages
members of both the nuclear and the extended family to help one another in times of need and can serve as a buffer against stress (Organista, 2007). Guarnaccia (1998) found that African-American families have denser, larger social networks and rely on them for help to a greater degree than families of European descent, exemplifying how caregiving and cultural attributes can support consumers’ engagement in treatment. Within some Asian cultures, SMI is considered punishment for offenses committed by the consumer; perceived as a family problem, recovery requires members to call upon obligations and make sacrifices for the wellness of the entire family (Hsiao & Van Riper, 2010). Despite families experiencing a great deal of stress, Doornbos (1996) reports that they desire and do develop coping skills when engaged by providers.

Efforts that perceive families, as consumers define them, as important instrumental and affective supports have proven to be effective and underscore the need to engage “families” in consumer service planning (Corrigan, Mueser, Bond, Drake, & Solomon, 2008). One such EBP, family psycho-education, has demonstrated consistent reductions in hospitalizations (Dixon et al., 2001; Pharoah, Rathbone, Mari, & Streiner, 2004).

Homelessness

The successful characterization of homeless persons as mentally ill draws on the reality that research consistently reports approximately “one-third to one-half of homeless people had severe psychiatric disorders” (McQuiston, Finnerty, Hirschowitz, & Susser, 2003, p. 669). This sizable cohort struggles with a complex interplay of SMI, including comorbid substance or trauma-related disorders (Bassuk, Dawson, Perloff, & Weinreb, 2001; Burt et al., 1999; Koegel et al., 1996; Najavits, Weiss, & Shaw, 1997; Smith, Meyers, & Delaney, 1998; Tsemberis & Eisenberg, 2000). One study indicated that almost half of those with SMI also experienced some sort of victimization (Lam & Rosenheck, 1998). In addition to finding more victimization among homeless persons with mental disorders, they experience more problems with health (Sullivan, Burnam, Koegel, & Hollenberg, 2000). This was supported in a New York City study which found that 69% of all hospital admissions from the shelter system were related to substance disorder or mental illness (Kerker et al., 2005).
Individuals who are homeless and have SMI have been known to travel the “institutional circuit” (Hopper et al., 1997) among acute facilities, shelters, the streets, and transitional residences, which contributes to their poor health status and their depiction as treatment resistant (Drury, 2003). Historically, technologies that were effective in engaging homeless people with SMI in treatment and housing were associated with increased costs (Rosenheck, 2000), although current EBPs such as ACT and Housing First/Pathways to Housing are proving to be cost effective (Tsemberis & Eisenberg, 2000; Tsemberis, Gulcur, & Nakae, 2004; Tsemberis, Moran, Shinn, Asmussen, & Shern, 2003).

Un/deremployment

The unemployment rate among individuals with SMI has been estimated to be as high as 85%, with long-term unemployment associated with a diagnosis of psychosis, severe symptoms, and a history of multiple hospitalizations (Goldberg et al., 2001). SMI is also significantly associated with reduced earnings whereas there is no statistically significant reduction in wages for individuals who have ever had a mental disorder (Kessler et al., 2008). Kessler and colleagues estimated the cost burden of lost productivity at $193.2 billion for the total population, with 75.4% attributable to reduced earnings and 24.6% attributable to a diminished probability of employment.

Approximately 50% of U.S. employers surveyed expressed reluctance to hire individuals with psychiatric histories and 75% expressed reluctance to hire individuals with histories of substance use who are currently taking antipsychotic medication (Scheid, 1999). Thus, despite federal legislation that prohibits discrimination based on disability, individuals with SMI continue to experience direct and indirect discrimination because of attitudes, structural disincentives, and generalized policy neglect (Stuart, 2006).

In a recent multisite randomized trial, researchers found that persons with schizophrenia were less likely to be competitively employed but fared better when enrolled in evidence-based supportive employment programs even when “at study baseline, individuals with schizophrenia had significantly higher levels of symptoms, greater number of months hospitalized over their lifetimes, younger ages of illness onset, lower education, poorer work histories, and lower work motivation than those without schizophrenia” (Cook et al., 2008, pp. 43–44). In addition, supported employment models designed to place first/fast track employment appear more effective than models emphasizing training first (Corrigan &
McCracken, 2005). Hence, evidence-informed supported employment programs can assist a wide range of individuals with SMI and may be especially beneficial in improving competitive employment rates among those with clinical issues that have historically impeded workforce retention (Bond, Drake, & Becker, 2008; Drake & Bond, 2008; Rosenheck et al., 2006).

Criminal Justice Involvement

Some suggest that individuals with SMI have not been treated in the community but instead the institutions in which they are warehoused has changed; specifically, Lurigio and Swartz (2000) state that prisons, jails, and detention centers have become the de facto treatment setting given their overrepresentation in criminal justice settings. A U.S. Department of Justice report on the mental health status of U.S. prison and jail inmates reported that more than 700,000 inmates reported symptoms of mental disorder or a history of treatment for mental disorder in the past year (Bureau of Justice Statistics, 2006). Specifically, the Department of Justice found that 56% of state prisoners met the definition of SMI, with 43% reporting a history or symptoms of mania, 23% reporting symptoms or a history of major depression, and 15% having experienced psychotic symptoms such as hallucinations or delusions.

The complex interaction between SMI and incarceration is exacerbated by issues of recidivism, gender, and homelessness (Braithwaite, Treadwell, & Arriola, 2005) so that consumers experience a revolving door with high rates of recidivism (Lamb & Weinberger, 2001; Lovell, Gargliardi, & Peterson, 2002). As early as 1995, Roesch, Ogloff, and Eaves underscored the need for collaborative approaches, especially bridging researchers to criminal justice systems, in order to improve the identification, prevention, and treatment of individuals with SMI. A SAMHSA study examined collaborative jail diversion models for SMI consumers with forensic involvement. The study found that aggressive linkages to services and implementing nontraditional models of care were central to decreasing recidivism (Steadman et al., 1999). In particular, Lamb, Weinberger, and Gross (2004) spoke to the need for mental health professionals to work with police departments to prevent the unnecessary criminalization of consumers with SMI. More recently, Loveland and Boyle (2007) explored the effect of different models of case management and found that intensive models that provided integrated addiction treatment led to a reduction in arrests and incarceration. The proliferation of drug treatment and mental health courts and other programs address these issues.
Stigma

Stigma is embedded in the systems from which consumers seek services, and this exacerbates the barriers they must overcome. Stigma, or the loss of social status and discrimination generated by negative stereotypes that have become linked in a particular society to a particular human attribute such as mental illness (Link & Phelan, 2001), impacts individuals as soon as they have officially been labeled by the treatment establishment (Link, Cullen, Struening, Shrout, & Dohrenwend, 1989), especially among individuals with COD (Link, Struening, Rahva, Phelan, & Nuttbrock, 1997; Luoma et al., 2007; Semple, Grant, & Patterson, 2005). For example, the public image of individuals with SMI as violent is perpetuated in our language, media (Wahl, 2006), and research (Lidz, Banks, Simon, Schubert, & Mulvey, 2007) although they are more likely to be victims of violence rather than perpetrators (Choe, Teplin, & Abram, 2008; Teplin, McClellan, Abram, & Weiner, 2005). In fact, even the most well-meaning professionals and advocates stigmatize consumers by judging their capacity to recover and by limiting consumers’ decision making instead of allying with them (Wagner & Cohen, 1991). Such subtleties of bias reinforce professional power and control of oppressed and stigmatized communities (Forest, 2003) and inform consumers’ experiences of their illnesses and its consequences and whether they use available services (Rüsch et al., 2009).

RECOVERY IN CONTEXT

The President’s New Freedom Commission on Mental Health (2003) emphasized the need to transform how mental health services are delivered and insisted that consumer voice and participation was necessary in creating this change. Despite resistance, the Recovery Movements, which encompass a number of ideological stances, have been central in maintaining momentum toward systemic change. Yet, the definitional debate surrounding SMI impacts how recovery is incorporated into systems change and, in point of fact, whether it is viewed as a legitimate intervention. If SMI is a function of specific disorders, then it will be conceived as severely limited, whereas if SMI is fundamentally the embodiment of the interplay between social, psychological, and biological processes, it has much greater potential. The arguments around recovery are examined here in order to make these issues explicit and to assist program planners in understanding the implications of the various choices on program design and delivery.
Defining Recovery: More Debate

The concept of recovery as used by consumers in mental health movements has a long history. Although it has been suggested that recovery is a new paradigm that began in the 1970s (Allott, 2003; Anthony, 1993; Schiff, 2004), it has also been noted that consumers and advocates have been questioning psychiatric practices and the custodial care of individuals with SMI for hundreds of years (Chamberlin, 1990; Chamberlin & Rogers, 1990; Roberts & Wolfson, 2004; Van Tosh, Ralph, & Campbell, 2000). Some suggest that increased interest in recovery stems from cross-cultural and local research findings that between 25% and 65% of study participants with SMI recover from mental disorders, in particular schizophrenia (Davidson, O’Connell, Tondora, & Evans, 2005; Jacobsen & Greenley, 2001). However, others attribute it to the strength of the psychiatric patients’ liberation movement that began in the 1970s and took root in the 1980s (Anthony, 1993; Frese & Davis, 1997; Schiff, 2004; Van Tosh & del Vecchio, 2000; Van Tosh et al., 2000). Chamberlin (1990), recognized as the psychiatric patients’ liberation movement founder, places the consumer movement within an evolving—and uncompleted—consciousness-raising process begun during the Civil Rights Era. Similarly, there continues to be some disagreement regarding the appropriate term for consumers themselves. For many in the consumer movement, it is ultimately a political statement that speaks to consumer control and ownership of the definitions and processes (Schiff, 2004).

Given the politics inherent in the concept, depending on whether one questions survivors, ex-patients, consumers, professionals, former substance abusers, or other constituencies, the definition of recovery itself will differ (Davidson et al., 2005). Roberts and Wolfson (2004) suggest that the different definitions are captured by two competing streams: The first emphasizes both clinical and social functioning, which approximate what is understood as “cure” and the second focuses on personal and subjective elements that speak to accommodations to the illness. Davidson et al. (2005) suggest that much of the confusion results from the various uses of the term “recovery” as related to physical conditions, trauma, substance use, and SMI. They elaborate that the emphasis on a return to a normative state is dominant in discourses related to physical disability and rehabilitation.

The term recovery was coined by substance self-help groups (White, 1998, 2000) and, therefore, the addiction-based definition emphasizes abstinence from substances through admission of the substances’
impact on the individual’s life and maintaining sobriety through vigilance and community support. And, lastly, they suggest that the mental health usage of the term reflects the individual reclaiming life and creating a narrative that is not defined by the disease or by others.

The most frequently cited definition is that offered by Anthony (1993). He states that recovery is:

a deeply personal, unique process of changing one’s attitudes, values, feelings, goals, skills and roles. It is a way of living a satisfying, hopeful, and contributing life even with limitations caused by the illness. Recovery involves the development of new meaning and purpose in one’s life as one grows beyond the catastrophic effects of mental illness.

However, many consumers have viewed this definition as a subversion of the lived meaning of recovery owing to its emphasis on limitations (Fisher & Chamberlin, 2004). In the competing National Empowerment Center (NEC) definition, they emphasize consumer control and full recovery regardless of continued symptoms or the use of medication (Ahern & Fisher, 2001; Fisher & Chamberlin, 2004). A definition deemed more acceptable to many across disability communities is that offered by SAMHSA (2005):

Mental health recovery is a journey of healing and transformation enabling a person with a mental health problem to live a meaningful life in a community of his or her choice while striving to achieve his or her full potential.

In this definition, focusing on a transformative journey, choice and meaning are viewed as promoting increased awareness and reducing stigma and discrimination (NCD, 2008).

Recovery: Principles and Models

Regardless of the definition, however, there are some key components recognized as necessary in recovery approaches. SAMHSA (2005) offers the following 10 components as essential to recovery in mental health: (1) self-direction; (2) individualized and person-centered; (3) empowerment; (4) holistic; (5) nonlinear; (6) strengths-based; (7) peer support; (8) respect; (9) responsibility; and (10) hope.

Fisher and Ahern’s (2001) Empowerment Model is based on the experiences of persons with different diagnoses and is meant to capture the general process of recovery from SMI. These models are described in Table 1.1.
Recovery as a Process

Essential to an understanding of recovery is acknowledging it as a self-ascribed, nonlinear process including, for some, the continued presence of symptoms, use of medication, and limitations or impairments (Fisher, 2004; Roberts & Wolfson, 2004). The relationship a consumer has to the symptoms and/or limitations is telling; in a qualitative study of recovery narratives among individuals with schizophrenia, Shea (2010) found that

### TABLE 1.1

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<td>Emotionally Distressed</td>
<td>Loss/Stress</td>
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<td>Severe Emotional Distress (SED)</td>
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<td>Mentally Ill</td>
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<td>Recovery &amp; Healing emotionally</td>
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a sense of living with rather than "engulfment" by the disease was central. Thus, the central issue from the standpoint of the consumer is in distinguishing the disorder or disease from the personal experience of it as an illness. Indeed, how consumers interpret their experience of SMI has significant consequences for recovery: Studies examining narratives of people in recovery have found that the transformation from an illness-dominated sense of self to one that is viewed as competent and as having agency is critical to the recovery process (Mancini, 2005; Mancini & Lawson, 2009; Mancini & Rogers, 2007; Ridgway, 2001).

Yet, the recovery movement is clear that the process of recovery is an individual transformative process that is not easily reduced or necessarily viable for others. What has been found is that the active management of the recovery process for consumers is an opportunity to reclaim their voice and power within all the systems that comprise their lives so that they can fully participate in society and perform roles other than "client." Approaches that engage individuals in such active efforts around disorders that can be disabling are understood as "recovery management models." These models emphasize fostering consumers’ capacity to overcome stressors and achieve wellness-enhancing goals (Brown et al., 2008), including the development of recovery capital or the institutional and social resources (e.g., social networks, employment, education, and self-determination) that sustain recovery and promote inclusion in society (Granfield & Cloud, 2001). Recovery management stresses problem solving and normalizes the varied trajectories in recovery, which demedicalizes the illness experience and recovery process (Ellison & Dunn, 2006). The Empowerment Model and recovery management models appear to share recognition that a consumer’s capacity to maintain wellness and an experience of being in recovery or recovered is dependent less upon the resurfacing of symptoms than upon the marshalling of supports and strategies during the inevitable situational stressors and crises in life.

Recovery’s Evidentiary Base

The emerging evidence base for consumer-directed and consumer-delivered approaches comes from many fields, including mental health, education, and addictions. Within mental health several meta-analyses have demonstrated that self-help programs had positive outcomes as compared to no treatment (Gould & Clum, 1993; Kurtzweil, Scogin, & Rosen, 1996; Scogin, Bynum, Stephens, & Calhoun, 1990). One-to-one peer support programs have produced improvements in many areas of functioning (fewer crisis events, fewer hospitalizations, improved social
functioning, reduction in substance abuse, and improvements in quality of life) as compared to those not receiving peer-delivered services (Carolyn et al.; Klein, Cnaan, & Whitecraft, 1998; Resnick & Rosenheck, 2008; Salzer, 2002). Also, case management delivered by consumers has been found to be as effective as professional services (Chinman, Rosenheck, Lam, & Davidson, 2000; Dixon, Hackman, & Lehman, 1997; Solomon & Draine, 1995). Researchers have found that relationships built around mentoring and coaching for information, affiliation, and instrumental supports likelihood of employment, and retention. There is evidence that consumer programs increase empowerment and participation, and impact service utilization (Forquer & Knight, 2001; Rogers et al., 2008; Trainor, Shepherd, Boydell, Leff, & Crawford, 2002). More recently, consumer-run self-help groups and individual support within a chronic management program based on the Flinders model were found to improve illness self-management and quality of life (Lawn et al., 2007) in employment (Bauldry & McClanahan, 2008).

Peer Support

Peer support incorporates life-meaning and spirituality (Laudet, Morgen, & White, 2006) and has been found to be positively associated with changes across nine areas of recovery and empowerment (Corrigan, 2006). The value of peer support derives from the powerful effects that social relationships are now widely recognized as having on both physical and mental health (Berkman, Glass, Brissette, & Seeman, 2000). As with individuals with SMI, assertive linkage, rather than passive referrals, and utilization of various supports improved outcomes for individuals with severe substance-related disorders (Scott, Foss, & Dennis, 2005; White & Kurtz, 2006). Thus, rather than seeing self-help and community supports as after-care once abstinence is achieved, they are themselves legitimate pathways to recovery.

RECOVERY-ORIENTED SYSTEMS OF CARE

Within the addictions sector, the drive toward Recovery-Oriented Systems of Care (ROSCs) and the evidence supporting it are instructive to mental health planners and administrators. The development of ROSCs began as substance treatment was reconceptualized from an acute model of stabilization and abstinence to that of a chronic care model wherein substance disorders are recognized as having different trajectories (White, 2005, 2006, 2008). The central elements in ROSCs are the same
components identified by SAMHSA as components of mental health recovery (Bellack, 2006).

Informing ROSCs is the recognition that formal treatment too often views relapse as failure on the part of consumers rather than as an indication that the appropriate combination of services and supports matching the particular cultural, spiritual, and racial/ethnic needs of a consumer has yet to be identified (White et al., 2006). The underutilization of alternative pathways is especially problematic for persons of color given that they receive a lower quality of care; even when socioeconomic factors or access-related factors are controlled (Smedley et al., 2002), they appear to respond differently to standard treatments (Le Fauve et al., 2003; Venner et al., 2003).

**Recovery and System Transformation**

As repeatedly emphasized in multiple federal reports encouraging systems transformation (Smedley et al., 2002; USDHSS, 2001), providers, policy makers, and program planners need to fundamentally reframe their understanding of recovery and its role in improving the lives of consumers with SMI. A decade ago, Norcross (2000) suggested that “A massive, systemic, and yet largely silent revolution is occurring in mental health today and is gathering steam for tomorrow: self-help efforts without professional intervention.” Nevertheless, achieving this transformation is fraught with tension. The movement to a consumer-directed system will be difficult within a mental health system that is run by professionals who have the power to establish etiology, define nosological systems, and determine illness course. Just as the concept of EBP has altered the structure and thinking of the health and social service systems, it is (hopefully) causing us to question our individual and institutional roles in favoring certain professional technologies while resisting more “exotic” or less established ones (e.g., our historic dismissal of medicinal herbs).

**Recovery, Communities, and the Embodiment of Social Factors**

The attractiveness of the Empowerment Model of Recovery (Fisher & Ahern, 2001) derives from an understanding of the vulnerability of all individuals to mental illness and to SMI when faced with loss, trauma, and stress in an environment without sufficient supports, both before and after formal diagnosis. That is, whether a mental disorder becomes disabling is not solely a function of a disease but a product of the availability
Mechanic and Tanner (2007) note that today health and social services are much more cognizant of the poverty issues and “upstream factors” that contribute to the inequalities and inequities as experienced by and embodied among these populations and groups, but policy and programming are hampered by assessments of blame typically focused at the individual level. They also note that as we further empirically substantiate “that neighborhood and community context affects health and welfare beyond personal characteristics and resources, it makes clear the need to design improved interventions at the community level” (Mechanic & Tanner, 2007, p. 1228). The development of approaches, such as ROSCs and livable communities, offers the promise of such community efforts.

Beginning in 2004, the National Council on Disability (NCD) developed a model for individuals with disabilities that incorporates consumers’ preferences for independent living and those environmental factors that facilitate autonomy (NCD, 2004a, 2004b, 2006, 2007, 2008). Based on these findings, the NCD developed a number of models of livable communities and has offered one specifically for the needs of individuals with psychiatric disabilities. Six essential elements of communities were identified across the models: (1) affordable, appropriate, and accessible housing; (2) accessible, affordable, reliable, and safe transportation; (3) work, volunteer, and education opportunities; (4) access to health and supportive services; (5) participation in civic, cultural, social, and recreational activities; and (6) adjusting the physical environment to ensure inclusiveness and accessibility (NCD, 2008). For individuals with SMI, and individuals with psychiatric disabilities who experience homelessness, criminal justice involvement, and substance dependence, a key issue is housing.

Although access to affordable housing is a concern among all disabled populations—and increasingly an issue for all Americans—the hindrance for individuals with SMI is that housing continues to be viewed within custodial terms. In 1999, through Executive Order 13217 and the Supreme Court decision in Olmstead v. L.C. the federal government underscored the right to housing in the least restrictive setting for individuals with mental disabilities in accordance with the American with Disabilities Act (ADA) (PL 101-36). Both the executive order and the decision affirmed that “Unjustified isolation or segregation of qualified individuals with disabilities through institutionalization is a form of disability-based discrimination.”

Yet, consumers with SMI continue to be perceived as unable to participate in community life. And, the issue of housing and institutionalization
is a central fulcrum in the definitional debate regarding SMI and in society's appropriate response. The concept of ontological security—that is, a place engendering feelings of well-being, safety, constancy, and security (Neale, 1997; Padgett, 2007) for individuals with SMI, and for recovery communities in general—connects the experiential sense of belonging to social interaction within spatial and ideational communities. The relevance is that communities provide individuals with some measure of ontological security, the capacity to create meaningful narratives, perform daily routines, and provide direction. Linking this more explicitly, recovery provides a social network that offers rules, repertoires, and shared views. It serves as a counterforce or counter-discourse to biomedical explanations and directives and to moralistic or etiological discourses that frame consumers as disempowered by, and eternally subject to, their condition or vulnerability.

The lack of social integration among consumers with SMI is captured by Fisher (2009), who writes: “For most of us consumer/survivor/ex-patients (c/s/x’s) our central issues are discrimination, helplessness, and isolation.” Much of current social and health programming, however, pays insufficient attention to assisting consumers to meaningfully connect with others in terms of both physical and emotional/psychological space: Interventions are directed at or provided to individuals with SMI rather than engaging them as full partners. And, while shelter has been increasingly recognized as necessary, it is assumed that it is also sufficient in the creation of ontological security, although this is not the case. This is wonderfully captured by Ware, Hopper, Tugenberg, Dickey, and Fisher (2007), who suggest that without consequential civic activities, relationships, respect, and political voice consumers “living outside the hospital may be described as in the community, but not of it” (p. 474) (emphasis added).

Communities and social networks are critical to recovery because it is through them and within them that consumers can strengthen their capacity to create empowered, hopeful narratives that are syntonic with their experiences. Indeed, social networks are crucial to the management of crises in that they provide havens or a sense of belonging and being assisted, bandages as they provide routine emotional support and coping under stressful conditions, safety nets that lessen the impact of acute crises and chronic difficulties, and social capital (Wellman & Gulia, 1992). Hence, interventions that include volunteerism, mutual aid, citizen participation, and organizational decision making have been shown to have positive outcomes as consumers take on “valued roles” (Brown, Shepherd, Merkle, Wittuk, & Meissen, 2008; Brown, Shepherd, Wittuk, & Meissen, 2007; Petersen & Zimmerman, 2004; Rowe et al., 2007) and acquire recovery capital (e.g., social networks, self-determination, employment, etc.).
In terms of program development and planning, constructing more socially integrated interventions requires maximizing collaborative and coalitional approaches to service design and delivery. The emerging evidence from mental health and drug treatment courts as well as ROSCs demonstrates that approaches which capitalize on existing services and create *interventive communities* that promote consumer education around a range of available services and support, and that respect consumer choice, work. Indeed, these strategies recognize that service aversion and treatment ruptures are inherent within a system that is fragmented and poses barriers to access and quality care. As new models are created, further exploration and development of the inclusive livable community framework may prove useful in that it can serve as a “unifying and universal construct” (NCD, 2007) for all individuals with disabilities. Individuals with SMI will remain socially isolated—as well as persons in other “vulnerable populations”—if we continue “segregating people by their disabilities into specific housing and other … programs [which] is discriminatory, creates barriers to services, and divides the disability community, as well as creating ‘disability ghettos’” (NCD, 2000, p. 46). Furthermore, if we are to truly benefit from evidence-based and promising practices funders, program planners and administrators need to break down the barriers and silos created by different disability sectors, to develop cross-disability coalitions to advocate for such communities, to promote cross-fertilization, and to transfer innovations and models that may be relevant across multiple sectors (NCD, 2004b).

**Recovery, Language, and Stigma**

Today, the continued variable and interchangeable use of the three terms underscores the fact that consensus has yet to be reached in defining SMI (Parabiaghi, Bonetto, Ruggeri, Lasalvia, & Leese, 2006). Beyond custom, “the often chronic and persistent nature of mental illness” (Woodward et al., 2008, p. 1297) may reinforce and justify perpetuation of the use of CMI and SPMI despite a federally legislated definition. The observation in practice, research, and life is that many individuals with SMI have an illness experience that is nonlinear, burdensome, and unrelieved—both to the person and their families and to society. For example, some have recently constructed operational definitions of CMI in research with individuals who are also homeless (Koegel, Burnam, & Farr, 1998; Sullivan, Burnam, Koegel, & Hollenberg, 2000; Wolf, Burnam, Koegel, Sullivan, & Morton, 2001). Such terminology prevails because it can quickly and
easily capture and communicate a complex individual process that, while
unique, is not exceptional.

Although the use of CMI and SPMI may make it easier to communicate
a complex phenomenon, their use has consequences for individuals living
with SMI. In particular, it is noted that the term “chronic” can serve as
coded language or as a “demeaning euphemism” (Chinman et al., 2001)
for individuals with SMI or particular diagnoses. In normalizing the term
chronic, Bachrach noted, “I think the only one that is really bizarre is
SPMI, which stands for severe and persistent mental illness. In discussions
I have heard people with illnesses referred to as speemies” (Talbott, 2000).
While the categorization of individuals to a single term or acronym may
economize attention and simplify understanding, it also stereotypes, deval-
ues, and dehumanizes those to whom it is applied—which impacts consum-
ers’ willingness to enter care (Grossman, 2004). This is apparent with other
stigmatized service groups, especially individuals experiencing homeless-
ness and persons with substance disorders, who are similarly characterized
as “chronic,” reinforcing characterizations of individuals and populations as
“difficult,” hopeless and unresponsive to interventive strategies and ser-
vices. While professionals may use chronic, “speemies,” and other terms
to facilitate communication, they preserve distance between “us” and
“them,” perpetuate stigma, and ultimately require a redoubling of efforts
to connect with and be purposefully used by those seeking service.

CONCLUSION

Transforming the mental health system requires that we incorporate and
embrace inclusive approaches. The persistence of definitional dilemmas
for SMI and recovery highlights the fundamental ideological, epistemo-
logical, and methodological schisms among those in the biomedical and
social sciences. Yet, as more individuals are affected directly or impacted
politically, economically, or in their own communities, the public will look
to professionals and policy makers for answers. And, of course, as is cur-
rently the situation, they will hold those working in these arenas accountable
if our attempts at system transformation fail. Hence, it is critical to integrate
family members, consumer allies, and communities in the change process.

Current research efforts will hopefully advance our comprehension of
how folk and popular technologies work and can contribute to our under-
standing and treatment of SMI and, more importantly, can engage consum-
ers (and allies) in meaningful, culturally appropriate ways that develop
their sense of integrity and self.
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**Legal and Legislative Citations**


