Directions for Future Patient-Centered and Comparative Effectiveness Research for People With Serious Mental Illness in a Learning Mental Health Care System

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About the Cover

Judith Wachner
I live in California and have always loved to draw, especially faces. I don’t like to plan, but just my hands tell the story. Art makes me quieter and calmer inside and is my best medicine.

Introduction to the Supplement: Directions for Future Patient-Centered and Comparative Effectiveness Research for People With Serious Mental Illness in a Learning Mental Health Care System

Lisa Dixon, MD

This supplement, while ambitious in scope, presents its major concepts with elegance and clarity. In this critical appraisal of mental health services treatment and outcomes, the authors have extended the utility of research findings by systematically gathering data on the experiences and preferences of numerous stakeholders. Key among the report's conclusions is the need for patient-centered, patient-developed measures that can be used at all levels of a learning system to assess service provision approaches, compare treatment interventions, and improve outcomes.

This group of measures, the report argues, should reflect the values and preferences of service users and other stakeholders while being customizable to individual treatment goals. Some measures may be helpful to all stakeholders, and others may be relevant primarily to specific groups such as service users, family members, clinicians, or organizational leaders. While such instruments are essential for improving mental health care, frameworks and methods for studying the treatment process from the studied person's view are rare and nascent in their development.

An important insight of the report is that reliable information, while critical, has its limitations. At a minimum, the effort to make patient-centered measures useful requires that structures be in place to routinely assess service users' preferences and goals, measure progress toward those goals, and facilitate the flow of information from consumers to clinicians to organizational leaders and back down the chain. However, information alone will not substantially improve quality of services or individual outcomes. The complexity and variability of stakeholder needs make tools such as pay for performance seem like hammers, when jeweler's tools might be closer to what is appropriate.

The report, thus, suggests that strong, supportive relationships—between clinicians and service users and among organizational staff at various levels—are the key to sustainable improvements in treatment and outcomes. Organizational practices and cultures that nurture such relationships are therefore critical, given the strong implication of this report that the therapeutic and recovery-enhancing relationships between users and professionals/clinicians/providers are the essential—and most endangered—element in mental health services. Administrative, fiscal, and policy impediments to forming such relationships must be addressed rather than regarded as inevitable.

While there are plenty of talented, trained people to provide face-to-face services to individuals with serious mental illnesses, the necessary policies, funding priorities, and workplace settings for making optimal use of these talents are in short supply. The recommendations of this report, which places multiple stakeholder perspectives at the heart of its analysis, represent a sea change from most service improvement approaches, which have typically taken a narrower view. In this era of health care reform and rapid change within health systems, numerous natural experiments provide important opportunities for focusing research in these critical areas.

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The authors deeply appreciate the considerable support, commitment, and contributions of the staff at the Kaiser Permanente Center for Health Research, Harvard Pilgrim Health Care, and the University of North Carolina at Chapel Hill. We express our gratitude to Center for Health Research project staff Thomas Knapp and Shannon Janoff; our librarian, Daphne Plaut; and our editors, Jonathan Fine and Jill Pope; and to Harvard Pilgrim HealthCare staff Darren Toh, ScD, Beth Syat, and Kimberly Lane. We would also like to thank the stakeholders, technical experts, and consultants below for giving their time so generously.

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Executive Summary

Background

People with serious mental illnesses have benefited from consumer advocacy, dissemination of recovery-promoting practices, and state and federal reforms such as parity and legal protections. At the same time, many people continue to experience significant disability that may affect cognition and their ability to engage and interact with others, guide and adhere to treatment, and navigate successfully within institutions and systems. Despite recent efforts to improve the quality of care for this diverse group, vexing challenges remain. These include the difficulties of changing the focus of care from acute symptom control and relapse prevention to long-term, recovery-focused care, coordinating care among different providers, and adapting interventions to different settings with multiple, fluctuating funding streams.

Both the Patient Protection and Affordable Care Act and numerous state initiatives have strong potential to improve patient-centered outcomes if corresponding patient-centered measures are developed and implemented. These reform efforts present important opportunities for researchers to evaluate alternative delivery models and to integrate service users into the process of developing both services and patient-centered outcome measures.

The primary goal of this report is to provide the background and theoretical framework necessary to shift the focus of existing care systems and research programs away from short-term clinical outcomes and toward long-term, recovery-focused outcomes that are patient-centered and can be used to facilitate learning within health systems. Our primary audience includes researchers, funding agencies, and policy makers, although this report may also be of interest to clinicians and service users.

Approach

We worked with stakeholders (payers, providers, service users, and consumer advocates) and technical experts to develop a definition of "care delivery intervention" for individuals with serious mental illnesses, a theoretical model of a care system to serve this population, and an analytic framework and key questions to guide future research. We also conducted a narrative review to illuminate the complexities that must be addressed when considering system change. Finally, we used the model of care, analytic framework, and narrative review to identify patient-centered measures and metrics, key research questions, and high leverage points in the system—those places where a small amount of change-related effort is likely to produce large results.

Results

Definition of Care Delivery Intervention. Recognizing the key roles of the mental health consumer movement, autonomy, and choice in the shifting climate of medical and mental health care, we defined "care delivery intervention" based on several foundations of patient-centered care and services: (1) a focus on the outcomes most important to service users, (2) collaborative partnerships focused on care solutions that build strong consumer-provider relationships, (3) ongoing exploration of service users' reasons for seeking or ending care, and (4) ongoing provision of information relevant to the service user and the consumer-provider dyad.

Theoretical Model of Care: A Learning Service System for Individuals With Serious Mental Illnesses. The theoretical model of the care delivery system was developed to be a *learning* system that (1) is patient centered and patient directed to the greatest extent possible; (2) encompasses services beyond those typically provided in clinical or medical settings; (3) recognizes the dynamic nature of service users' needs and desires over time, thus includes ongoing assessment and adaptation of services; and (4) is responsive to feedback and functions, with the goal of continuously improving service delivery and patient-centered outcomes.

Analytic Framework to Guide Future Patient-Centered Outcomes Research and Comparative Effectiveness Research. The analytic framework, intended to guide and highlight opportunities for research that evaluate all components of a mental health system, contains six key topic areas: (1) resource acquisition and distribution; (2) populations served; (3) the delivery system, including delivery structures, organizations, and providers; service packages; and delivery methods and characteristics; (4) patient-centered outcomes; (5) delivery system and provider performance measures; and (6) feedback systems and methods.

Narrative Review. The components of our narrative review, developed in collaboration with stakeholders and experts, corresponded to the six primary domains of our analytic framework noted above. The findings from our review informed key questions for comparative effectiveness and patient-centered outcomes research.

Stakeholder Perspectives Our research review led to several key conclusions about stakeholder perspectives:

1. Consumers, families/carers, and providers predictably diverge in their assessments of consumer needs for services, and in their assessments of consumers' status and outcomes.

2. Demonstrable progress has been made in engaging stakeholders in evaluating treatment and services and in formulating federal, state, and local policy. Organization and financing models, however, are often taken as inevitable and trump many of the expressed opinions and evidence from these groups and individuals.
3. The most commonly agreed upon needs of stakeholders include choice, respect for persons, safety and material living needs, and competence of care.
4. Processes of collaboration in consumer-provider relationships are complicated and easier to imagine than achieve.
5. The unintended consequences of treatment receive scant attention in outcomes research. As a result, services and systems lose the opportunity to be self-correcting, learning systems.
6. People come to health and mental health systems with a variety of beliefs about the nature, causes, and consequences of mental illness. Cultural competence requires recognition of such differences.

Service User and Carer Involvement in System Design and Redesign, Research and Evaluation, and Development of Patient-Centered Outcomes Collaboration in constructing knowledge and assessing outcomes of treatment and services is central to a patient-centered system of mental health services. Consumers possess knowledge, skills, and conceptual frameworks that are needed in the research process. Such resources are essential to determining which questions are posed, the methods used for data collection and analysis, and the ways in which results are interpreted.

Resource Acquisition and Distribution Resources for providing services to people with serious mental illnesses are largely acquired and distributed through the public sector and, in particular through state Medicaid programs, which vary significantly in terms of funding, benefits, and delivery organizations. Overall, these financial structures have resulted in cost savings to states and private health plans, reductions in out-of-pocket costs for consumers, reductions in emergency department use, and increased crisis referrals. There is significant variation, however, in outcomes, suggesting that the details of the financing structures are important.

Care and Service Delivery for Individuals With Serious Mental Illnesses: Structures, Service Packages, Delivery Methods, and Delivery Characteristics Evidence exists for a number of methods and characteristics of care delivery systems and services that are necessary, if not sufficient, to achieve improved patient-centered outcomes for people with serious mental illnesses. Existing reviews, however, underscore the need for better definitions and constructs as well as methodologically rigorous research using measures that are validated for this heterogeneous population.

Patient-Centered Quality Improvement in Mental Health, System and Provider Performance Measures, and Methods of Feedback To improve the patient centeredness and quality of services provided to individuals with serious mental illnesses, we have proposed a patient-centered learning system of care that adapts to feedback over time. We reviewed six types of quality improvement activities for potential use to promote system learning and adaptation: (1) electronic health records (EHRs) and health information technology, (2) audit and feedback procedures, (3) pay-for-performance, (4) public reporting of performance data, (5) implementing patient-centered, evidence-based practices and guidelines, and (6) process-improvement initiatives. Evidence is weak for the effectiveness of most of these initiatives in medical settings, and little is known about their impact in behavioral health settings.

Feedback System and Methods for a Learning System Despite national calls for significant health system changes, the last two decades of health care reform and quality improvement efforts have produced, at best, slight to modest improvements in outcomes for individuals with serious mental illnesses. Complexity science offers an alternative approach to understanding and improving systems. Although there is a large and varied literature on this topic, only some of this has been tapped by health care and mental health services researchers.

Discussion and Conclusions

Despite recent efforts and improvements in approaches to service delivery, we have encountered many conflicts and disconnects while producing this report—between the type, structure, and funding of services and the needs of consumers; between the processes of service delivery across settings and over time; and between traditional clinical outcome measures and the outcomes favored by the individuals receiving care. There are also significant disconnects between the perspectives of providers, families/carers, researchers, and consumers.

Thus, we were faced with the difficult task of developing innovative and emergent approaches to reduce the disconnects described above, building upon and gleaning as much useful information as possible from a research base with pervasive flaws. As a result, this report has no doubt perpetuated some of these same flaws. With that caveat in place, we offer a brief summary of our most important conclusions:

1. We lack sufficient outcome measures that have been developed by or in concert with service users, or evaluated rigorously by service users. Development of these measures is crucial and should be a primary aim of mental health research in the near future.

2. Information regarding the outcomes that service users value the most and least remains limited. Developing a clear and representative understanding of the most common values among service users, cultural differences within and across these values and understanding the full range of these values, should be a primary aim of the next generation of mental health services research.
3. Some attempts have been made to link individual outcomes to service packages, service characteristics (eg, continuity, therapeutic relationship), and performance measures, but consistency within and across outcome measures is lacking, and the measures used are fraught with problems when viewed from a patient-centered perspective. The mental health system needs feedback methods based on new patient-centered outcomes that are causally linked to services, processes, and structures.
4. To more appropriately target changes in processes of care and institutional structures that affect outcomes, we must link patient-centered outcomes to process- and structure-related measures.
5. There is a great need for patient-centered measures that can be aggregated for use at the organizational and system levels, as well as research developing effective methods for providing feedback using aggregated data.
6. More research is needed to compare the relative effectiveness of the many interventions that have been developed for individuals with serious mental illnesses. Such studies must include real-world patients with complex problems.
7. Financing of care and services are complicated and structured in ways that prevent coherent, coordinated, and integrated service delivery. Health care reform is providing rare opportunities for researchers to compare innovative methods of organizing and financing care.
8. As in other areas of the health care system, stakeholders may value and desire services that are not effective; strategies, policies, and methods are needed for managing and communicating the results of comparative effectiveness research in such situations.
9. In the context of systems, information alone is not adequate to produce system changes, although it is essential to the redesign process. Complexity science provides an alternative perspective regarding the factors that are likely to produce changes in systems (eg, organizational culture) and improvements in the outcomes those systems produce.
10. New methods and collaborative processes are needed to resolve the inherent tension between the needs and perspectives of researchers, quality improvement managers, policy makers, clinicians, and consumers.

We challenge comparative effectiveness and patient-centered outcomes researchers to develop methods that incorporate the perspectives of service users for unique and individualized assessment, intervention, and outcomes. At the same time, researchers must produce the evidence necessary to allow the mental health care system to improve the services it delivers to individuals with serious mental illnesses and the outcomes those services seek to address.

The opportunities associated with health care reform are many, and business as usual, with its incremental efforts to improve outcomes, is no longer possible. Researchers, administrators, policy makers, and clinicians are at a crossroads. It is time to take on the challenge of producing learning systems that can provide real patient-centered and patient-directed care to individuals with serious mental illnesses.

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Introduction

People with serious mental illnesses can and do lead meaningful and productive lives, and many are engaged in the process of recovery, both with and without mental health services. Consumer advocacy, dissemination of recovery-promoting practices, and state and federal reforms, such as parity and legal protections, have led to incremental improvements in the quality of services and life opportunities for people living with serious mental illnesses. Nevertheless, many people continue to experience significant disability, whether episodic or enduring, which affects cognition and ability to engage and interact with others, guide and adhere to treatment, and navigate successfully within institutions and systems.[1–4] Despite recent efforts to improve the quality of care provided to this diverse group, persistent and vexing challenges stand in the way of promising and well-intended reforms.[5] These challenges include changing the focus of care from acute symptom control and relapse prevention to long-term, recovery-focused care; constructing coherent and integrated services; coordinating care among different providers; adapting interventions to very different settings with different goals and multiple, fluctuating funding streams; and renovating service delivery settings where high staff turnover is the norm and continuity of care and good therapeutic relationships are the exception.[5–8]

The complexity of the current system is illustrated in figure 1, which lists the many factors affecting care systems and the individuals they serve, as well as the sectors that provide services, the services provided, and the ways in which these services affect individual outcomes. Falling through the cracks in this system is common,[9,10] as is incarceration,[11] and efforts to date to improve the quality and coordination of care have encountered significant barriers even in the midst of successes (see Vannoy et al[12] for a telling example).

Adding to this complexity are the many system changes now in progress, most notably resulting from the Patient Protection and Affordable Care Act (ACA), which is expected to significantly expand affordable health care coverage to more Americans by requiring individuals to have health insurance, expanding Medicaid eligibility[13] and Medicare drug benefits,[14] improving the health care delivery system, eliminating exclusions related to preexisting conditions,[15] and controlling costs. The ACA also includes provisions for mandated mental health and substance abuse treatment that will increase the services offered and extend them to a wider population.[16] At the same time, state and federal budget reductions complicate implementation of the ACA. Medicaid expenditures in almost every state are being reduced prior to the 2014 mandated expansion, and the national debt reduction bill signed by President Obama on August 2, 2011, calls for significant federal spending cuts in the upcoming decade. In addition, the effects of sequestration on Medicare and other health-related programs are likely to be significant.[17,18] These changes are expected to alter the funding landscape for the expansion of Medicaid under the ACA and will have important implications for the capacity of our mental health service system.

These developments present important opportunities and challenges for researchers. The density and sprawl of the current system, especially at a time of great change, speak to the need for a systematic method of organizing research and policy efforts to understand and improve its functioning. Implementation of state-level mechanisms for tracking and detailing ACA-related transitions in health care may provide rich data sources for monitoring types and delivery of care and patient outcomes, enabling comparative effectiveness research (CER) on a broad scale. Meanwhile, the changes brought about by federal spending cuts—particularly to Medicaid and Medicare—will provide important opportunities for studying different methods of organizing and financing mental health care.

While these research opportunities are promising, the science is hindered by a lack of common understandings and definitions and theoretical frameworks that guide our understanding of how delivery interventions affect outcomes. Nonlinear interdependencies among system elements create an additional set of difficulties. Frameworks are needed that encompass all levels of the system, from financing and organization of care to linkages between service sectors, and that detail how these factors affect care delivery, including individual-level coordination of care, treatment engagement, and treatment continuation. Just as important, research and policy must be informed by the real-world contingencies and pragmatics of service delivery, incorporating both practice-based evidence and evidence-based practices (EBPs).[19] Without a relevant theoretical framework, we risk a piecemeal approach that is much less likely to produce significant changes in the system or results that can be integrated in a coherent manner.

This supplement is designed to provide such a guiding framework. The need is abundantly clear from the current state of services for people with serious mental illnesses, and from the uncertainty surrounding the near-term future of these services. If disability is to be limited, recovery fostered, and individual outcomes and quality of life improved, then all involved parties—researchers, funders, policy makers, clinicians, and consumers of

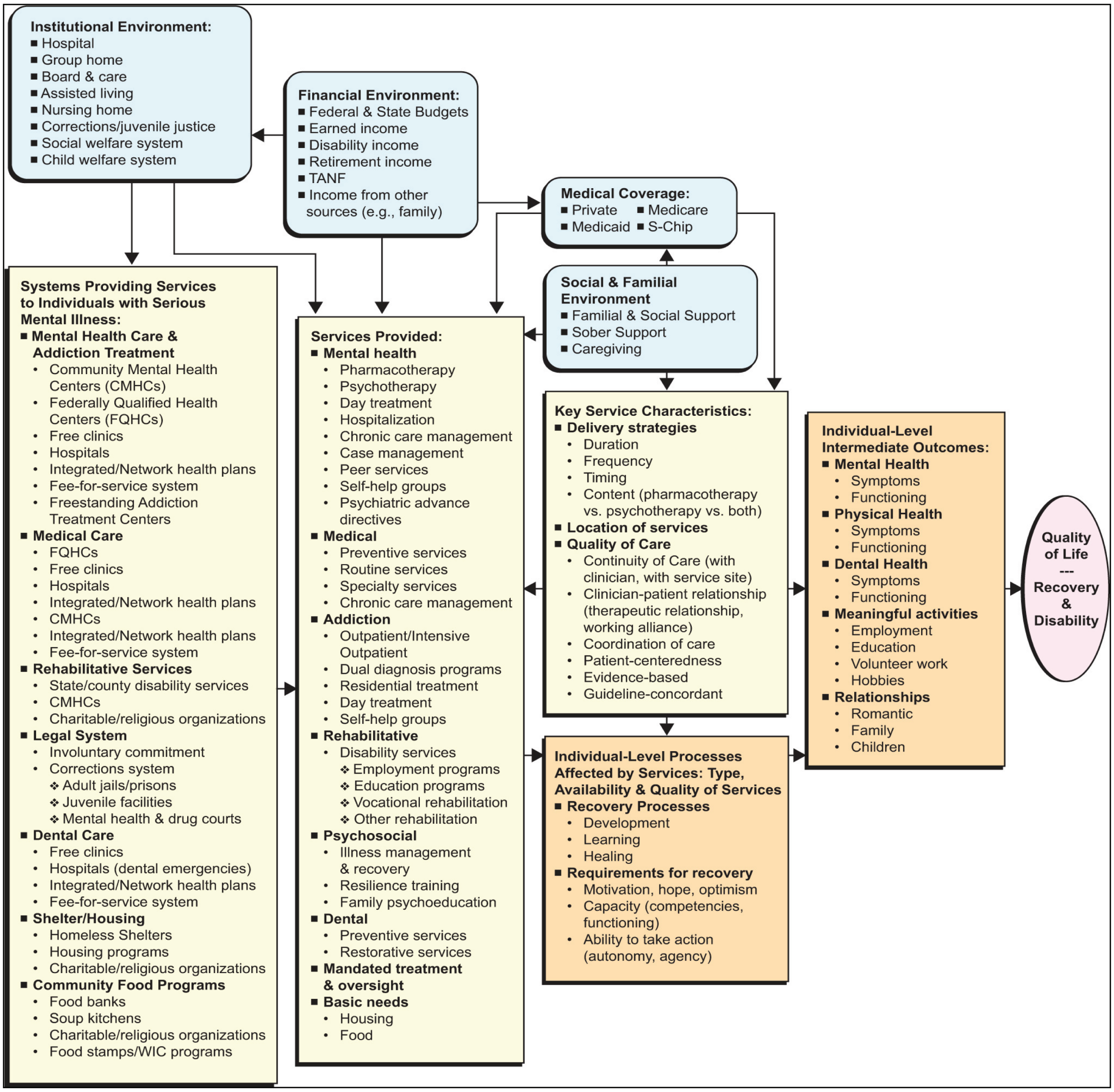


Fig. 1. Overview of the system serving individuals with serious mental illnesses, and relevant contextual factors.

mental health services—need integrated frameworks to guide research, policy, and care decisions.

Objectives

The background for this report originated in a series of meetings held in 2010 by the Agency for Healthcare Research and Quality (AHRQ). AHRQ gathered a diverse group of stakeholders to discuss issues and identify research gaps and needs related to serving people with serious mental illnesses.[20] Stakeholders identified several priorities:

- Conduct CER on service structure and delivery.
- Shift the research framework from an acute to a chronic care model (CCM) for individuals with serious mental illnesses.
- Develop more appropriate outcomes, measures, and metrics consistent with this model.
- Develop an appropriate infrastructure for both CER and patient-centered outcomes research (PCOR) methodologies to support longitudinal studies.
- Increase awareness of the central role of the therapeutic relationship in improving individual outcomes.

Our work was designed to provide the guiding framework needed to achieve these overarching objectives. To develop that framework, we pursued six strategic goals: First, we developed a stakeholder-driven definition of care or service delivery interventions for individuals with serious mental illnesses. Such a definition was necessitated by the wide range of needs for services and the systems providing those services. For example, individuals with serious mental illnesses die significantly earlier than their peers without mental illnesses,[21–23] with a large proportion of this early mortality attributable to preventable causes.[24,25] At the same time, many individuals with serious mental illnesses are either homeless or live in substandard housing,[26] even while the evidence is convincing that improved housing leads to improvements in both physical and mental health.[27] While such links demonstrate a clear need to address housing problems in this population, existing funding streams and methods of organizing care have made it difficult to bridge this important gap within the purview of existing care systems.[26] With these complexities in mind, we defined *a care or service delivery intervention* to reflect the full range of services needed, with the understanding that efforts to improve patient-centered outcomes will call for a more integrated and comprehensive approach to service delivery.

Based on this definition, we developed a patient-centered and patient-driven theoretical model of the system of care—our second goal. This model then informed our third project aim: to construct an analytic framework to guide future CER and PCOR programs designed to improve individual-level, patient-centered outcomes. The model and analytic framework were informed by stakeholders, technical experts, and the results of our fourth project aim: a narrative literature review. We used this review, in combination with stakeholder and expert feedback, to revise the model and framework and achieve our fifth goal: to identify key questions and leverage points in the system, where change is most likely to occur. High leverage points are those where a small amount of change-related effort will produce large changes in the system.[28,29] Our sixth aim was to identify measures and metrics corresponding to the model of care, the analytic framework, and the key questions and leverage points identified. This work was also carried out as part of the narrative review process.

Limitations

We addressed only the system providing services for adults; a similar analysis and report is needed for the child mental health system. Also, despite the prevalence of substance abuse issues and treatment among individuals with serious mental illnesses, it was beyond the scope of our report to include an analysis of and recommendations for the addiction treatment system. To bridge this gap, we have included a section addressing services for individuals with dual diagnoses. We also note that many of the conclusions drawn here are likely applicable to the addiction treatment system.

It was also beyond the scope of this report to identify existing systems of care that are functioning as learning systems. A recent Institute of Medicine Report entitled "Best Care at Lower Cost: The Path to Continuously Learning Health Care in America"[30] provides clear suggestions and approaches for creating the kinds of system we propose here.

Finally, we wish to recognize that the term *patient* remains controversial and is particularly unwelcome for some stakeholders and mental health service users. We have thus used alternative terms, including *consumer* and *service user*, whenever possible. At the same time, we were constrained by the need to use the well-established terms *patient-centered outcomes research* and *patient-centered outcomes* in order to situate this report in the context of other health system reform efforts.

Methods

Engaging Stakeholders and Technical Experts, and Clarifying Foundations

Our first task was to convene a stakeholder panel, a technical expert panel, and consultants (see Acknowledgments) to guide and inform our work. The individuals selected for these panels represented groups that are experienced and invested in care outcomes for people with serious mental illnesses, including individuals with mental health diagnoses. Concurrently, we reviewed seminal publications we felt should inform our work, including three Institute of Medicine (IOM) reports[7,31,32] and a recent monograph on criminal justice interventions for individuals with behavioral health problems.[33] Key concepts and ideas from these publications, two of which were suggested by our technical expert panel, served as the foundation for our work and are summarized briefly below.

Foundational Materials

Quality of Care. The IOM's Crossing the Quality Chasm[31] report called for improvements in six dimensions of health care performance: safety, effectiveness, patient centeredness, timeliness, efficiency, and equity. The report also asserted that such improvements are impossible within the existing system of care. Pointing to inherent system design flaws, the authors submit that better care requires a new design that is scientifically valid and that creates reliable systems in place of old, unreliable ones. Changes were proposed at four levels: the experience of patients, the functioning of small units of care delivery (microsystems), the functioning of the organizations that support microsystems, and the environment of policy, payment, regulation, accreditation, and other factors that shape the behavior, interests, and opportunities of the organizations. This hierarchical model is based on the contention that quality of actions at the second to fourth levels should be defined and evaluated by their effects at the first, patient-centered, level.

The report also provides a rationale and framework for redesigning the US health care system at each level. Most relevant for our work were the following suggestions: (1) changes should be bold, explicit, uniformly espoused, comprehensive, and patient centered; (2) changes should tie quality issues more closely to patients' experiences, costs, and social justice; (3) care should be patient centered, with each patient in control of their own care; (4) care should be customized, transparent, and based on a high level of accountability to the patient; (5) care should be knowledge based and supported by information systems that put knowledge at the point of use; (6) care should be system minded with the system assuming responsibility for coordination, integration, and efficiency across what have been traditional boundaries and barriers; and (7) care should be based on a high degree of cooperation among clinicians. The report adopted a complex-adaptive-systems approach (see Feedback Systems and Methods for a Learning System)[34–41] to system redesign and proposed 10 simple rules for the redesign process (see figure 2). (Crossing the quality chasm: A New Health System for the 21st Century by Committee on Quality of Health Care in America; Institute of Medicine Staff. Reproduced with permission of National Academy Press in the format "republish in print" via Copyright Clearance Center.)

The authors of the report recognize that redesign becomes more difficult, and the evidence weaker, as one moves from the microsystem to organizational level. Nevertheless, they recommend redesign at the organizational level in at least six areas: (1) more robust systems for identifying best practices and ensuring they become standards of care; (2) better use of information technology to improve access to information and to support decision making; (3) more investment and persistence in improving workforce knowledge; (4) more consistent development of effective teams; (5) better coordination of care within and among organizations (especially for patients with chronic illnesses); and (6) more sophisticated and extensive measurement of performance and outcomes.

Finally, the report recommends changes to payment systems to remove barriers to improvement of care; research and demonstration project agendas to understand barriers to such changes; high-level, system-wide dialogue and research on redesigns of professional education and credentialing systems; and legal and regulatory reform to make these systems more conducive to continual improvement. They also argued that to implement the suggested system redesign, the United States needs a directed strategy with national leadership, aims, and specific objectives. The ACA can be seen as an attempt to develop and implement such a strategy.

	Old Approach	New Approach
1	Care based primarily on visits.	Care based on continuous healing relationships.
2	Professional autonomy drives variability.	Care is customized according to patient needs and values.
3	Professionals control care.	The patient is the source of control.
4	Information is a record.	Knowledge is shared freely.
5	Decision making is based on training and experience.	Decision making is based on evidence.
6	"Do no harm" is an individual responsibility.	Safety is a system property.
7	Secrecy is necessary.	Transparency is necessary.
8	The system reacts to needs.	Needs are anticipated.
9	Cost reduction is sought.	Waste is continuously decreased.
10	Preference is given to professional roles over the system.	Cooperation among clinicians is a priority.

Fig. 2. IOM's crossing the quality Chasm's[28] 10 simple rules for microsystem redesign (used with permission).

Quality of Behavioral Health Care The IOM's report entitled Improving the Quality of Health Care for Mental and Substance-Use Conditions[7] built on the Crossing the Quality Chasm[31] report and specifically addressed behavioral health disorders. The report makes two overarching recommendations: (1) health care for mental and substance-use problems and illnesses must be delivered with an understanding of the inherent interactions between the mind/brain and the rest of the body and (2) the aims, rules, and strategies for redesign set forth in *Crossing the Quality Chasm* should be applied throughout behavioral health care on a day-to-day operational basis, but tailored to reflect the characteristics that distinguish care for these problems. The report recommends that organizations promote patient-centered care in several ways. First, they should incorporate informed patient-centered decision making with active patient participation in design and revision of treatment and recovery plans, use of psychiatric advance directives (PADs), and provision of information on the availability and effectiveness of treatment options. Second, organizations should adopt recovery-oriented and illness self-management practices that support individuals' preferences for treatment (including medications), peer support, and other elements of a wellness recovery plan. Third, organizations should maintain effective formal linkages with community resources to support service users' self-management of illness and recovery.

The report also addresses the roles of health plans and direct payers, recommending that they pay for peer support and illness self-management programs that meet evidence-based standards; provide consumers with comparative information on the quality of care provided by practitioners and organizations (and use this information themselves when making their purchasing decisions); and remove barriers to and restrictions on effective and appropriate treatment that may be created by copayments, service exclusions, benefit limits, and other coverage policies.

The authors recognize a number of challenges to achieving these goals in behavioral health, including stigmatization and discrimination of service users, the belief that consumers pose a danger to themselves or others, and the belief that service users with behavioral health problems are unable to make decisions about their own treatment. In response, the report advocates four approaches at the organizational and clinical level to reduce stigma and support individual decision making: (1) make support of consumer decision making a default organizational policy; (2) involve consumers in service design, administration, and delivery; (3) provide decision-making support to all consumers, including those under legal restrictions, mandated treatment, or other forms of coercive intervention; and (4) support illness self-management practices for all consumers, and formal self-management programs for individuals with chronic illnesses.

In addition to these reports, our technical expert panel also recommended that we review parts of the IOM report *Cancer Care for the Whole Patient*: *Meeting Psychosocial Health Needs.*[32] In addressing the effects of a serious chronic illness on the whole person—a concern as relevant to mental health as to cancer—the report recommends services beyond those typically provided by medical systems. The report defines psychosocial health services as those "services that enable patients, their families, and health care providers to optimize biomedical health care and to manage the psychological/behavioral and social aspects of illness and its consequences so as to promote better health" (p. 82–83).

The report's authors propose a comprehensive approach for delivering psychosocial services to patients with cancer. First, they recommend identifying patients with psychosocial needs that are likely to affect their health or health care. Second, they suggest working with patients to develop appropriate plans for connecting them with appropriate psychosocial health services, supporting them in managing their illness, coordinating their psychosocial and biomedical health care, and following up on care delivery to monitor the effectiveness of services and determine whether any changes are needed. The report emphasizes that effective patient-provider communication is central to all these components.

The report also lists a number of psychosocial components of whole person–based services for cancer patients, which appear equally applicable to individuals with serious mental illnesses:

- Providing information about illness, available treatments, health, and services
- Help in coping with emotions accompanying illness and treatment
- Peer support programs
- Counseling/psychotherapy
- Pharmacological management of mental/emotional symptoms
- Comprehensive illness self-management/self-care
- Assistance in changing behaviors to minimize the impact of disease
- Behavioral health promotion interventions

In addition, the report lists important material and logistical resources for whole-patient care. These apply equally to individuals with serious mental illnesses and include:

- Help in managing disruptions in work, school, and family life
- Family/caregiver education
- Assistance with activities of daily living/instrumental activities of daily living
- Legal protections and services
- Cognitive testing and educational assistance
- Financial advice and/or assistance
- Financial planning and counseling, including management of day-to-day activities (eg, bill paying)
- Insurance counseling (eg, health, disability)
- Eligibility assessment/counseling for other benefits (eg, social security)
- Supplemental financial grants

Behavioral Health and Criminal Justice. Finally, because many individuals with behavioral health problems find themselves involved in the criminal justice system, our technical experts recommended reviewing a report by Epperson et al[33] entitled *The Next Generation of Behavioral Health and Criminal Justice Interventions: Improving Interventions to Improve Outcomes*. This monograph acknowledges the host of factors contributing to justice involvement (Epperson, M., Wolff, N., Morgan, R., et al. The next generation of behavioral health and criminal justice interventions: Improving interventions to improve outcomes. Rutgers University Center for Behavioral Health Services & Criminal Justice Research; 2011.), considers the differing etiologies of these problems and their associated symptoms, and suggests approaches for addressing the full range of challenges that affect justice-involved individuals with behavioral health problems (see figure 3). The authors describe approaches to providing services that address the interactions between mental illnesses, addictions, and antisocial pathologies. They

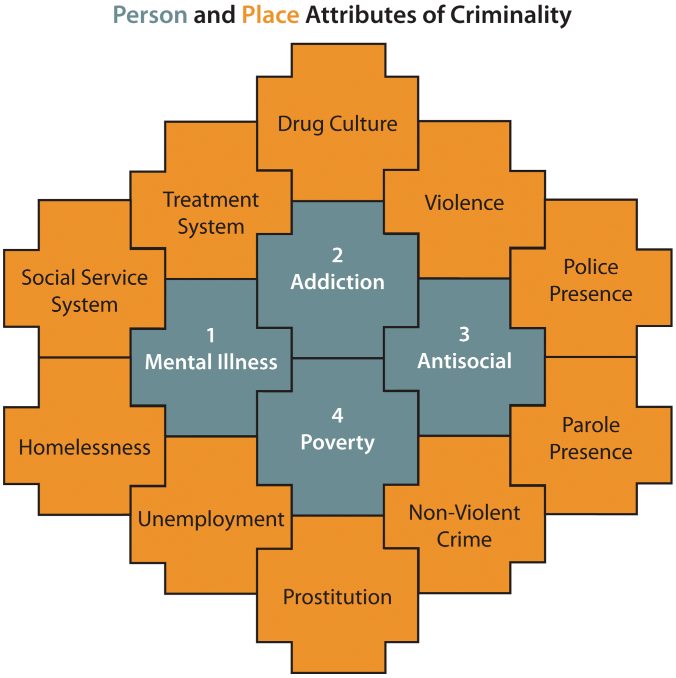


Fig. 3. Factors contributing to justice involvement[30] (used with permission).

also argue that expecting mental health treatment to be the sole solution to these numerous problems, rather than one component of a multipronged solution, may be the primary cause of intervention ineffectiveness to date.

Recommendations and considerations were based on a daylong workshop with key informants. Representatives from community-based programs serving justice-involved individuals with serious mental illnesses were invited to share their perspectives on the role of behavioral health interventions for this population. Several themes emerged from the workshop. For example, because of meager funding and resources, the basic needs of justice-involved individuals (eg, food and shelter) must be met before other needs are addressed. In addition, services must be integrated and coordinated, clients must be seen holistically, and EBPs, while important, must be approached flexibly and considered in light of their feasibility. Finally, philosophical approaches matter (eg, recovery orientation vs punishment orientation) and require universal adoption.

The authors describe the wide range of problems that are common among justice-involved individuals with mental illnesses. These problems concern environment (poverty, boredom, housing, lack of opportunities, discrimination, stigma, close proximity to crime, and criminal culture); mental health (access to care, lack of services, compliance/adherence, and symptoms of the illness itself); criminal thinking (wanting things "easy," glorification of "outlaw values," lack of accountability, and criminal attitudes); family dynamics (family history of criminality, family drug abuse, lack of parental boundaries, lack of family support); cognitive and coping skills (lack of coping skills, difficulty with impulse control, entitlement issues, thinking errors, and difficulty managing frustration); social support (lack of prosocial support and lack of positive peers or role models; and victimization (sexual, physical, emotional, and psychological trauma).

Engaging justice-involved clients in addressing these problems can be quite difficult for providers. Numerous person-level factors contribute to this difficulty, including lack of motivation or insight, impulsive behavior, disorganization, lack of trust, fragile coping skills, hopelessness, antisocial attitudes and criminality, resistance to treatment, poor judgment, trauma (all types), family (lack of *or* intrusive), homelessness, learned behaviors, active substance abuse, and addictive behaviors. The authors emphasize that it is not enough simply to be aware of these co-occurring problems; rather, they must be direct intervention targets because of their link to relapse and recidivism. The report recommends the following approaches:

- Develop service structures and orientations to address co-occurring problems that interact in ways that can impair judgment and promote harmful conduct.
- Adopt and consistently implement a "person-first" value into engagement and recovery philosophies.
- Integrate evidence-based programs in ways that are sensitive to real-world considerations (eg, screening tools, staffing requirements, philosophies, manualized structures, outcome measures, fidelity methods) and social conditions (eg, employment, criminal justice encounters, housing).
- Integrate service modalities that address the different problems (eg, trauma, criminal thinking, substance abuse) that contribute to relapse and recidivism and build the skills that will support healthy and safe choices and conduct.

Finally, the authors counsel that to make such changes in service delivery, "buy-in" is needed at all levels within and between organizations and systems serving this population.

Developing a Care Delivery Intervention Construct

Following the formative reviews, our project team, consultants, and panels of stakeholders and technical experts held a series of iterative, consensus-building webinars to define a *care delivery intervention* for people with serious mental illnesses. Our wide-ranging process reflected the breadth of services required that may not be considered "care" in many medical contexts. We began with a brainstorming session to identify the needs of people with serious mental illnesses and the boundaries of what our definition should include. We aimed for a definition that would be accurate, useful for future CER and PCOR, and comprehensive without being untenable in scope.

Through our brainstorming sessions, we identified basic needs (food and shelter), universal needs, and human rights needs, the latter of which seemed relevant given the circumstances surrounding some care provision for this population (eg, involuntary commitment and treatment). We identified needs ranging from autonomy, dignity, respect, value, and freedom from discrimination and stereotype, to life enrichment, communication, and social support. We listed needs common to both medical and mental health care, such as access to collaborative, therapeutically oriented providers, coordinated services, and health information technology that allows data sharing between systems of care. We also listed the need for access to tailored approaches: culturally adapted interventions, gender-specific and life stage-sensitive interventions, and trauma-informed care (supplementary appendix A includes the master list from these brainstorming sessions).

Having produced a long list of needs, we then asked our stakeholder and technical expert panel members to generate ideas for a *care delivery intervention* definition that would address these needs. Provocative and thoughtful discussions ensued as the groups grappled with the task of narrowing the definition while sufficiently addressing the breadth of needs. A number of questions arose about the scope of the definition:

> "Is any intervention that tackles anything on the needs list a care delivery intervention?"
> "Do we include outreach to homeless? Nursing home care? What about the preventive impact of a comfortable, safe place to live? Where are the system boundaries?"
> "Is one of the key messages of this report that there is something about having serious mental illnesses that creates needs above and beyond the broad vulnerabilities in the general population?"

Participants also questioned assumptions about the current care delivery system:

> "Is the underlying assumption that the system isn't working as is? Are we asking how CER can be used to re-shape the system?"
> "Instead of fully broken, are we asking how the system can be more effective?"

Some began to think ahead about the implications of the definition for the later development of the model of care and analytic framework:

> "How are services best organized? By diagnosis? Age? Type of service?"
> "At the crux is the financing that supports the care delivery interventions, whatever they are."
> "What are the real policy and intervention tools that are available? Because we could try to cure poverty but we can't really do that."

Eventually, the groups began to coalesce around needs for the definition:

> "It needs to be broadly defined and dynamic."
> "It needs to be adaptive as tools change."
> "It needs to be individualized and person centered."
> "It needs to be accountable to individuals."
> "It needs to consider the desired outcomes."
> "It should be a system that promotes healing and recovery, not about coercion and control."
> "It needs to use the evidence base to support interventions that are consistent with what individuals want. This will allow movement forward toward better care and outcomes."

Following these discussions, we empaneled a subgroup of stakeholders and technical experts to work with us to develop a draft of the definition. The result was presented first to another subgroup of panel members and then to the broader group, using the extranet of the Developing Evidence to Inform Decisions about Effectiveness Network. After several rounds of feedback, including a face-to-face meeting with project staff and the full panel of stakeholders and experts, revisions were made to arrive at the final definition (see below).

Developing a Theoretical Model of the Care Delivery System

While the care delivery definition work group honed the definition, the project team moved ahead with developing the model of care. We set out to create a model that (1) accommodated the identified needs of the population, (2) accurately represented the clinical and service components identified through defining the care delivery intervention, and (3) could be used to guide our understanding of how delivery interventions, at different levels in the system, will affect particular patient-centered outcomes among people with serious mental illnesses.

In a series of webinars, our stakeholders and technical experts suggested numerous approaches to the model. Some were focused on chronicity or stage of illness:

> "Consider grouping by first episode. That is, those who have just been through a first episode would have a different sequence of events in the model than those who have a chronic condition."

Some approaches were focused on severity of illness and impairment:

> "Think about [DSM-IV] Axis IV issues like ability to care for basic needs, interpersonal functioning, productivity, income earning potential, and identify outcomes from these."

Some were focused on the setting where individuals would receive care:

> "Consider organizing by intervention setting."
> "If we organize by silo we may perpetuate what's been going on rather than recommending how to move beyond silos."
> "We don't want to split too much, but some splitting is required. For example, the homeless need services specific to them that are not needed by others."

Perhaps because members were already anticipating the end product, a suggestion was made to organize the model by care delivery interventions:

> "One goal of the framework is to demonstrate where we have and don't have evidence. Maybe we should organize the model by intervention. For example, here is an approach we need evidence for, here is another we [already] have evidence for."

Developing an Analytic Framework to Guide Future CER and PCOR

The analytic framework is a diagram, with corresponding narrative, that illustrates opportunities for systematic examination and comparison of novel and existing care delivery interventions. In addition to specifying the pathways by which these interventions are expected to influence patient-centered outcomes, the framework identifies leverage points in the system of care where PCOR and CER have the greatest potential for improving patient-centered outcomes. As such, the framework is intended to highlight the processes involved in care delivery and services that could be the focus of research, and to stimulate a new set of key questions whose answers could fundamentally address processes and outcomes at all levels in the model. It is also intended to emphasize the promise of natural experiments for examining innovative processes of funding, organizing, and delivering services and care. In addition to the narrative explaining the framework, we developed sets of key questions that need to be answered at key leverage points, and we identified known or possible risks for harms or adverse events that might result from interventions at these points.

We presented the draft analytic framework to our stakeholder and technical expert panels for comment and discussion and then revised it prior to the face-to-face meeting, where it was further refined. The final framework is presented below.

Definition of a Care and Service Delivery Intervention

As our first task, we defined *care and service delivery interventions* using the process described above. This definition is situated within the shifting climate of medical and mental health care, emphasizing patient-centered and recovery-oriented care in mental health and recognizing the central role of the mental health consumer movement in shaping these new directions. Our goal was to approach care and service provision research from a patient-centered perspective that assumes or fosters individual agency, autonomy, and choice. For the authors, experts, and stakeholders who have contributed to this definition, the key components of patient-centered care are the following:

- The focus of care and services is on the outcomes that are most important to individuals, who are considered in their cultural context and as whole persons.
- Care and services are based on a collaborative relationship between providers and service users, who focus on health promotion and prevention and come to agreement about the problem and solutions for management.
- The process includes ongoing exploration of service users' reasons for seeking or ending care.
- The process includes ongoing provision of information relevant to the service user and the relationship between service users and providers.

Based on these principles, we propose the definition presented in figure 4. (Terms Used and their Definitions: "Serious mental illness" is any psychiatric disorder of sufficient duration and severity to cause functional impairment that affects major life activities. "Organized delivery process" refers to strategies, protocols, or methods used to coordinate the planning, provision, or funding of services at the individual, practice, organization, or system level. "Services" includes interventions that address needs typically outside the scope of those addressed by the health care system (eg, education, employment, housing) and those addressed by the health care system. "Providers" is defined as persons providing care or services in an organized process of care delivery, including peer providers. "Surrogate" is defined as those person(s) identified and/or empowered by the patient to serve in his/her stead when the patient is unable to do so. "Preferred outcomes" are time-varying, dynamic, person-centered outcomes that accurately reflect, and are accountable to, the preferences, cultural sensitivities, life stage, and circumstances of the person. They include the following subjective and objective dimensions: psychological, cognitive, emotional, physical, social, spiritual, economic, and environmental.)

A patient-centered intervention for people with serious mental illnesses is defined as:

An organized process of care or service delivery that is directed by the person receiving services. Care and services are delivered collaboratively, attentively, and compassionately, with providers as partners who understand and respond to the person's perspectives, culture, and concerns. The delivery process is structured to educate, inform, guide, and assist the person to be a knowledgeable consumer of the services relevant to attaining the person's self-defined needs, goals, and outcomes, taking into account the person's individual circumstances.

All individuals, including those who have been diagnosed with a serious mental illness, have the right to direct their own care. People who are limited in their ability to direct their care as a result of acute symptoms or legal constraints should be provided with the support necessary to make as many care-direction decisions as possible. If a person is unable to make informed choices about his/her care, providers will rely on historically expressed preferences and values and, when available, psychiatric advance directives and designated surrogates to maximize the person's participation in decision-making about services and treatment. Care decisions made for persons when they are unable to direct their own care should be based on the premise that such decisions will enable those persons to make future choices about their care. Care and services provided to service users should take into account available scientific knowledge and the resources of the service system.

Fig. 4. Definition of a patient-centered care and service delivery intervention.

Culture and Collective Understanding in the Context of Patient-Centered Care

This section is based on feedback provided by Roberto Lewis-Fernandez, MD (personal communication, October 7, 2012) and adapted for use in this report. The majority of the text remains his.

A limitation of much patient-centered work to date is the individualistic perspective on which it is based, which reflects the growing individualism of mainstream culture. This perspective allows us to unthinkingly move from the individual to the health system as though nothing stood between them. In fact, individuals sit in communities—most often and immediately represented by families (nuclear and extended)—which transmit and create collective understandings of illness and care that shape, and are shaped by, individual views. If we focus solely on the individual, we risk ignoring these important forces and their roles in affecting outcomes.

How would a more collective understanding of culture make a difference? That is, what is wrong with the theoretical understanding of culture as a collective process that is refracted through the individual and therefore accessible to the project of patient centeredness by exploring each individual's views? By pursuing this purely individualistic approach, we would likely miss (or be delayed in discovering) the importance of alternate understandings of processes of care (eg, what recovery is, what constitutes treatment, which outcomes are valuable) because we would fail to notice their presence in whole communities. We would see individual peculiarities instead of common views held by substantial subgroups. Over time, we would find that our understandings do not apply to certain subgroups, and we would have to fund disparity-focused research to find out why. It is preferable to consider cultural perspectives now, when patient-centered care is being defined and developed, than to conduct remedial research later.

For example, how would patient-centered care work when a man in his twenties, with a diagnosis of schizophrenia, has a mother who makes all decisions about his care in the context of a community that holds that such an approach is appropriate? This describes the experience of many service users from immigrant Latino or Chinese communities. Or, consider the Fujianese community in New York City, in which a young man with schizophrenia is expected to work to pay his immigration expenses. A recovery priority for families of such men is to maximize employment capability because the family faces danger of retaliation if they cannot pay their debt. Such contextual, collective aspects related to care needs must be included in the individual-based, patient-centered model if we are to understand the people we are serving.

These young men could certainly express care needs to their providers, but the system would be more likely to react if the information were seen as applicable to a wider community. We risk giving short shrift to community-level issues when we examine issues only at the individual level. It is difficult for a provider or a health system to reorient approaches to care if they do not recognize that the individual variations they see among service users are parts of a powerful, collective system. It is far more efficient to discover the overall influence of the collective understanding and *then* reveal the individual views that fit within it.

That said, we still must understand service users as individuals and resist stereotyping them—a risk when we elicit personalized views of care from people who represent certain cultures, particularly our own. We take the collective background and understandings for granted and proceed to explore the views of the individual patient within this collective understanding. For person-centered care to work, we must reveal these collective understandings and choose the most appropriate among them when assessing the individual in front of us. Of course, the cultures and worlds we inhabit have porous borders; most people go in and out of different worlds every day as they go about their business, and these worlds continuously affect each other. By gaining knowledge about the various worlds inhabited by consumers, we can better understand the contextual nuances of expressed views and needs. To this end, health systems can acquire a wide range of information about the cultural groups they serve, providers can be trained based on this information, and personalized assessments can inquire about the views of family, friends, and community members who have influenced the person's views about care and services.

A Theoretical Model of the Care Delivery System: A Learning Service System for Individuals With Serious Mental Illnesses

Our patient-centered model of the service system for individuals with serious mental illnesses (figure 5) was based on four underlying assumptions. First, care and services should be patient centered and patient directed to the greatest extent possible. Because of the broad range of needs among members of this population, the model is designed to encompass services beyond those typically provided in clinical or medical settings. While the patient-centered approach implies a focus on one person, the model assumes that individuals live within communities and social networks, most often represented by families. These networks and communities create and transmit collective understandings of illness and responses to services that affect individual views. Our second assumption was that individuals' needs and desires change over time. As a result, the system must be responsive to those changes, adapting services and care as needed to achieve person-centered outcomes. Third, the care and service system must act as a learning system with the goal of continuously improving service delivery and patient-centered outcomes. Feedback and learning at the individual, provider, organization, and system levels must be used to inform and improve individual outcomes and

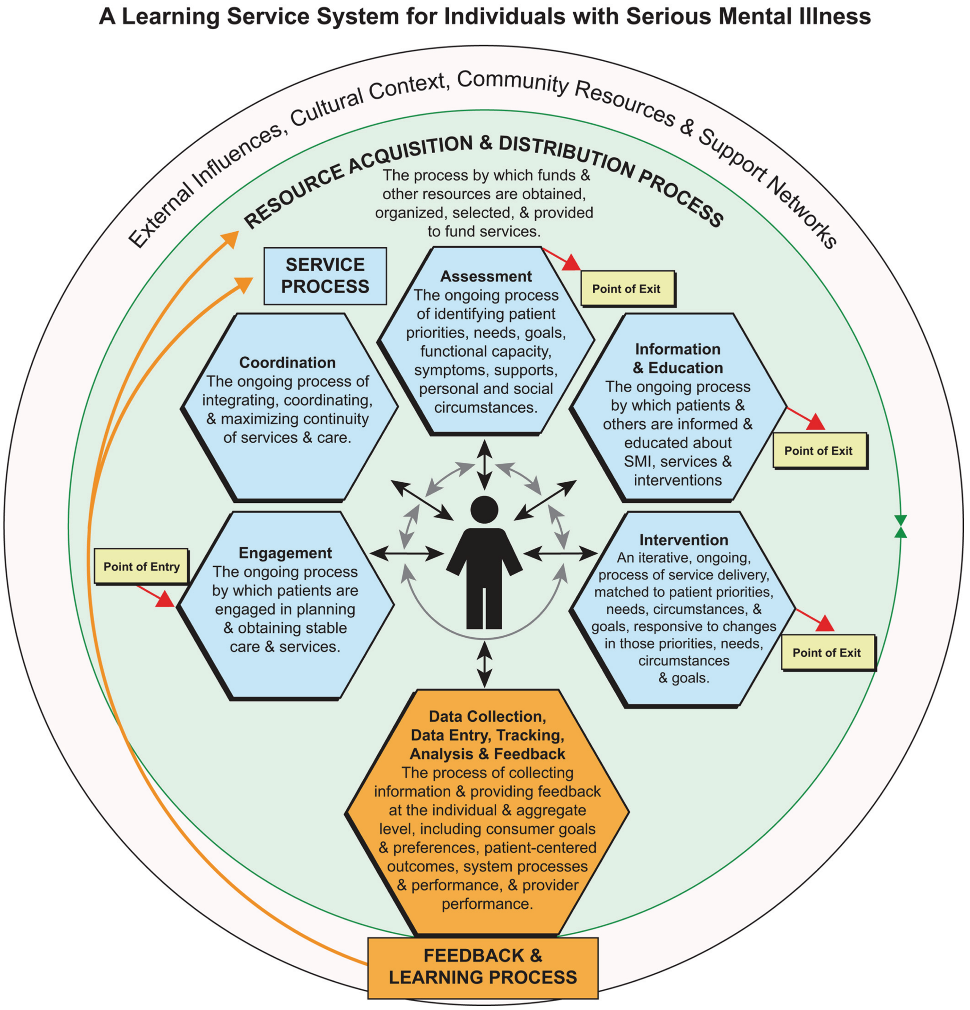


Fig. 5. Theoretical model of a learning care system for individuals with serious mental illnesses.

the process of care and service delivery at each of these levels. Without such systems in place, we will never know what works and what does not work to improve outcomes. Our last underlying assumption was that to truly improve care, feedback and assessment of effectiveness must accurately reflect patient-centered service processes and outcomes as evidence. In a learning system, aggregated patient-centered process and outcome measures should be used to facilitate improvements in performance at all levels. At the same time, performance incentives and requirements at the system, organizational, provider, and financial levels are best when they remain separate from process-improvement efforts. This maintains the integrity of the learning system by avoiding perverse incentives.

Analytic Framework to Guide Future Patient-Centered Outcomes Research and Comparative Effectiveness Research: Improving Individual Outcomes

Whereas our model of care depicts the process of care and service delivery as we believe it should be conceptualized, our analytic framework (see figure 6) is intended to guide future PCOR and CER programs. That is, the theoretical model is a clinical model, while the analytic framework serves to guide research by highlighting opportunities for evaluation of processes and outcomes. It is worth noting that separating these processes in the analytic framework does not preclude the use of common patient-centered outcome measures across framework components. For example, patient-centered outcome measures can and should be aggregated to create indicators of provider-, organization-, and system-level performance.

Narrative Review

To determine areas where research is plentiful and areas where more evidence is needed to improve care and service delivery to individuals with serious mental illnesses, we conducted a narrative review of the primary domains in the analytic framework. The results, summarized below, are not intended to be comprehensive in scope but rather demonstrative of the breadth of this system and the complexities involved in system change. When adequate review articles were not available, we conducted further searches to identify primary literature. We searched bibliographic sources including PsycINFO, PubMed/MEDLINE, Sociological Abstracts, Social Services Abstracts, the Cochrane Library, Google Scholar, Health and Psychosocial Instruments, and EconPapers, as well as Web sites of agencies and organizations such as the Substance Abuse and Mental Health Services Administration (SAMHSA), the Kaiser Family Foundation, the Urban Institute, and Mathematica Policy Research. We also asked our technical experts and stakeholders to suggest publications.

Our search strategy for identifying stakeholder perspectives was more comprehensive, including reviews, original research publications, and monographs, as well as first-person accounts and online sources (see figure 7). We also used these sources to identify additional materials for review.

Stakeholder Perspectives

In order to meaningfully assess and develop patient-centered mental health services and systems, substantial shifts are necessary in what we consider as evidence; how we collect, interpret, and apply evidence; and how we engage stakeholders in these processes. The expertise and knowledge of consumers, families, carers, and providers are often misunderstood, distorted, or mistranslated in outcomes research and analysis. Our review led us to several key conclusions about stakeholder perspectives:

- Consumers, families/carers, and providers predictably diverge in their assessments of consumers' status, outcomes, and needs for services. They differ in language, conceptual frameworks, the bases for their assessments, and the way they prioritize needs. These differences are most apparent in their definitions—and thus assessments—of recovery processes.
- Recovery is increasingly being translated into an outcome by researchers and policy makers. The condensation, standardization, and interpretation involved in mainstream outcomes research and evidence-based policy may obscure the nuance, complexity, and power of the recovery process. Consumer-directed and consumer-informed research is particularly salient here. It is important to distinguish between value-based and evidence-based outcomes and practices when assessing the effectiveness of services. Some treatments and services, and the qualities of their provision, are endorsed because they enact deeply held values, not necessarily because their effectiveness has been established.
- Demonstrable progress has been made in engaging stakeholders in evaluating treatment and services and in formulating federal, state, and local policies. Organization and financing models, however, are often taken as inevitable and trump many of the expressed opinions and evidence from stakeholders. Providers in particular are awash in reimbursement criteria and documentation, ever-changing requirements for accountability, and inadequate resources. These strictures make it difficult to promote the kinds of healthy working alliances with consumers and families/carers that produce continuous healing relationships.
- The most commonly agreed-upon needs of stakeholders concern qualities of person, place, and relationship. Choice, respect for persons, attention to basic safety and material living needs, and competence of care, are shared aspirations and expectations for mental health services. Therapeutic relationships and working alliances are the fulcrum of mental health services, but the facilitators and barriers to such partnerships have not received adequate attention in research, service design, or service provision.
- Collaborative service user-provider relationships are complicated and easier to imagine than achieve. The widespread deployment of peer providers within, and

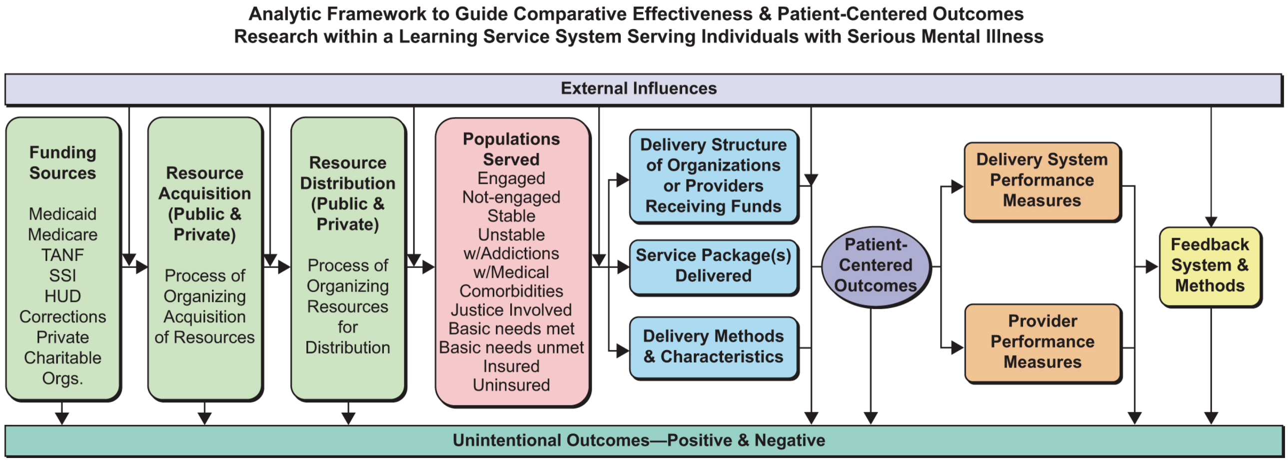


Fig. 6. Analytic framework to guide future comparative effectiveness and patient-centered outcomes research.

Search Strategy and Results: Stakeholder Perspectives

Search terms: mental health consumer, psychiatric patient, service user, mental health provider, clinician, psychiatrist, nurse, case manager, mental health shared decision making, mental health patient-centered care, family members and mental health treatment, mental health outcomes, therapeutic alliance, working alliance, empowerment, autonomy, basic needs, forensic psychiatric patients, innovative mental health services, peer providers, serious mental illness provider practices and practice interventions, coercion and outcome, seclusion, restraint, consumer run services, consumer-centered or directed outcome measures.

Inclusion: review, meta-analysis, and technical report overviews; summary analytic reviews of conceptual frameworks and models; empirical research within past 10 years specific to patient-centered mental health services, consumer needs and preferred outcomes and outcome measures, provider needs and interventions, family member needs and preferences, and consumer participation in service delivery, research, and policy.

Sources: Medline, BioMedCentral, PsychInfo, Cochrane Library, Google Scholar, CINAHL, PLoS, PubMed, NLM, schizophrenia.com, mindfreedom.com, PeopleWho.com, Somatosphere, DEcIDE Mental Health Consortium. Journal based searches: Psychiatric Services, American Journal of Psychiatry, Community Mental Health Journal, British Journal of Psychiatry, Psychiatry, Social Science and Medicine, Psychiatric Rehabilitation Journal, Journal of Health and Social Behavior, Psychosis, Psychological Medicine, Schizophrenia Bulletin, Culture, Medicine, and Psychiatry, Mental Health Journal, Journal of Mental Health Policy and Economics, International Journal of Social Psychiatry and Epidemiology.

Search Results: Total number of included publications: 335: Reviews and meta-analyses: 22; Consumer needs and preferences: 160; Consumer assessment of treatment, identification of needs and preferences, shared decision making, types of services, relationships with providers, coercion, safety, choice: 51; Consumers as Providers+ Consumer Peer Run/Directed Services: 39; Consumer Participation in Evaluation, Research, and Policy: 44; Consumer Driven/Produced outcome measures: 26; Family/carer needs and preferences: 20; Provider needs and preferences: 43. Note that some articles were classified in more than one category, for example, papers that compared consumer, family, and provider perspectives.

Fig. 7. Search strategy for review of stakeholder perspectives.

as adjunct to, mental health services has moved relatively swiftly, as has the number of consumer-operated services. It is important to assess these moves with the understanding that their goals and mechanisms differ from those of more traditional providers.

- The unintended consequences of treatment receive scant attention in outcomes research. As a result, systems lose the opportunity to be self-correcting entities. The use of coerced and involuntary treatment in hospitals and community settings, as well as the more subtle and pervasive manipulation of choice, represent possible sources of injury or harm for consumers, families, and even providers, and may keep people from seeking services that might be helpful to them.[42] And, as in other areas of medicine, consumers may want services or treatments that are ineffective or inappropriate. Providing patient-centered care in these circumstances can be challenging. It is essential to understand the service user's perspectives and goals, provide information about why the service is not recommended, and suggest alternative approaches.
- People come to health and mental health systems with a variety of ideas and understandings about what mental illness is and how to treat, cope, and live with it. These ideas are heavily influenced by collective understandings about the causes and consequences of illness. At the same time, the person receiving services is not merely a representative of his or her culture. Cultural competence requires recognition of difference, not stereotyping, and it requires that instead of making assumptions, we ask about the values, traditions, and practices that are part of the person's biography. Services and treatment relationships must be informed by and responsive to the relationship contexts of the person and the collective understandings they may share with others.

The following sections summarize reviews of research, meta-analyses, and empirical investigations published primarily after 2000 and examining the efficacy of services, treatment, and outcome needs and preferences of people with serious mental illnesses, family/carers, and providers. The focus is primarily on the evidence *from* and *about* these three stakeholder groups and their assessments of the effectiveness of services and systems of care for people with serious mental illnesses. After an analytic review of the evidence in each area, we identify gaps, limitations, and unintended consequences, and we suggest directions for future research to inform a learning system of care that is patient centered, effective, comprehensive, and recovery-promoting.

Service Users: Needs and Preferences

> The involvement of mental health service users in service delivery is a new and growing phenomenon. Such involvement is complex, given the history of paternalism in the mental health system, the power differential between service providers and service users, and the very differing views each group holds on multiple issues. Unless such differences are addressed, there can be no meaningful involvement. Service user involvement needs to apply to all aspects of

> the service delivery system, including professional training, service design, delivery, evaluation, and research. User/survivors, and their organizations, have developed a body of experience and knowledge that needs to be recognized and respected. Unless there are multiple opportunities for ongoing and open dialogue on these many difficult issues, real user involvement will not occur.[43(p20)]
>
> —Judi Chamberlin, author and activist

A central aim of this section is to respond to Chamberlin's eloquent call to recognize and apply the experience and knowledge of service users to improve service delivery. Along with primary consumers of mental health care (those diagnosed with serious mental illnesses), we include family members/carers and frontline providers. These three stakeholder groups live with, experience, and work in mental health services with unique proximity and intensity. The studies we reviewed confirm that attending to consumer assessments of services yields important information that can and should be used in learning systems of care. The evidence of differences between consumer, provider, and family/carer assessments and needs is substantial. The challenge is to translate the findings from these stakeholders into services and delivery processes and to develop the means with which to assess them.

The topics included in this review were derived from the stakeholder-generated list of needs and preferences, the input of expert consultants and stakeholders in each of these areas, the collaboration of our work group, and our *care delivery* definition and theoretical model of care.

Relationships With Providers The quality of consumer-provider relationships in inpatient and outpatient settings is arguably the primary influence on consumer assessment of services.[44] The foundation and primary referent of consumer needs and preferences for services is their desire for informed, respectful, engaged, collaborative, and flexible interactions with providers. Numerous studies document both the positive influence of working alliances and the negative impact of failed therapeutic relationships.[45,46]

In reviewing these findings, it is helpful to consider how the data are gathered and the concepts and frameworks for analysis. For example, "satisfaction" may be a limiting and perhaps inapt construct for assessment, as it fails to address consumers' expectations for services. Several suggestions for more accurate modes of elicitation and analysis, including system responsiveness, have been proposed as alternatives. Hopkins et al[47] reviewed 10 studies, published between 1998 and 2008, that measured system responsiveness to consumer expectations of inpatient psychiatric treatment. In assessing system responsiveness, the authors argue that attention is shifted away from general satisfaction with services and toward the link between what the person expects and what is provided. The components of responsiveness reviewed by Hopkins et al[47] included confidentiality, autonomy, respect for dignity, prompt attention, quality of amenities, access to social support, and choice of provider. The authors identified three primary themes in consumers' notions of respectful treatment: that the system provide a place of safety/refuge, that it provide inpatient programming, and that it support healthy interpersonal relations with staff and others. Brunero et al[48] echoed these findings, identifying "being happy with the service provided by the consumer support worker, having support for services on discharge, and feeling safe and secure on the ward" as significant predictors of reported satisfaction with inpatient care. Mason et al[49] pointed out that satisfaction with services should be differentiated from loyalty to a particular provider or treatment setting.

Happel[50,51] used focus group methodology to explore Australian consumers' views on effective services, how to evaluate them, and barriers to their success. Echoing the consistent findings about the importance of strong relationships with providers, Happel[50,51] found that consumers regarded responsiveness, follow-up, respect, and individualized support from clinical staff as essential to their recovery. Continued contact with and support from friends and relatives was also a key ingredient, as was the consumer's taking responsibility for his or her own circumstances and planning. With respect to barriers, informants identified staffing issues, lack of safety and security, isolation, and a focus by staff on the illness instead of the person. In another study, Mason et al[49] identified the cultural and religious competence of providers as important components of effective services.

Green et al[52] added an additional dimension to positive, trusting relationships with clinicians: longevity. Long-term relational continuity of care allowed development of close, collaborative relationships, fostered good illness and medication management, and supported consumer-directed decisions. Clinicians who were competent, caring, trustworthy, and trusting, and who treated clinical encounters "like friendships," increased willingness to seek help and continue in care. Statistical models showed positive relationships between recovery-oriented, consumer-driven care and satisfaction with clinicians, medication satisfaction, and recovery. Relational continuity affected satisfaction with clinicians, which led to improved quality of life (QOL). Ware et al[53] found similar results, as did Laugharne et al.[54] They found that choice, trust, and the ability to shift the balance of power as needed between the provider and service user occurred over time in the consumer-provider relationship. They cited personal disclosure about clinicians' own lives, common acts of kindness, and conversation outside clinical matters as key to this personal approach. As Green et al[52] found, service users viewed trust as a two-way process with responsibility shared between partners.

Researchers have made numerous attempts to operationalize working alliances or therapeutic relationships, as evidenced by the 15 or more measures developed to date. Bordin[55] proposed several key components of the therapeutic or working alliance: agreement on the goals and tasks of therapy, strong patient-therapist bonds, and positive views about the working process (eg, therapist skills, patient perception of therapist's ability to help). More concretely, identifying an unmet need is a proxy for therapeutic goals, and meeting previously unmet needs is a proxy for task effectiveness. The effects of therapeutic relationship type and strength on consumer outcomes, however, remain elusive and under investigation.[56] Priebe et al[57] reviewed the predictive strength of therapeutic relationship scores for outcomes in nine prospective studies, comparing hospitalizations, levels of symptoms, and functioning. While each study showed a positive relationship between working alliance and outcomes, no association was statistically significant, and the studies varied widely in sample size and methodology. In a companion review of 15 measures of therapeutic relationships, McCabe and Priebe[58] concluded that while no single scale had been adopted widely, each measure reviewed had acceptable psychometric properties. Their finding that positive therapeutic relationships consistently predict better short- and long-term outcomes deserves continued attention in measures development and the application of research results to service settings. Researchers must also account for the variability of treatment goals and settings, as well as other influences such as the voluntary or involuntary status of the treatment.

Providers face particular challenges in establishing positive therapeutic relationships with individuals experiencing psychotic symptoms. In such cases, providers may avoid discussions about the content of hallucinations or delusions out of concern that they will inadvertently collude with service users in their symptoms. This leaves both service users and clinicians feeling uncomfortable.[59] McCabe and Priebe[59] note a lack of systematic, theoretically informed training for providers regarding such situations, as well as a lack of research on best clinical approaches. There is some evidence that the therapeutic relationship predicts outcomes of complex psychiatric treatment programs in service users with psychosis, but more methodologically rigorous research is needed.[57] Fakhoury et al[60] evaluated the effectiveness of the therapeutic relationship between clinicians and a patient population deemed "difficult to engage." After controlling for other predictors, a positive therapeutic relationship predicted fewer hospitalizations and treatment adherence in new service users but not in established service users. In an Australian study measuring the effect of the working alliance on recovery for individuals with serious mental illnesses,[61] the authors found that changes in working alliance predicted recovery, but that changes in recovery also predicted the nature of the alliance. Therefore, the authors could draw no definitive conclusions regarding the causal direction of such relationships. Nonetheless, the study suggests that improvements in alliance positively influence gains in recovery and vice versa.

Summary and Implications Despite near-universal agreement that consumer-provider relationships are fundamental to meeting consumer needs and improving assessments of services, there is less certainty about whether and how these relationships contribute to consumer outcomes. This ambiguity raises interesting questions: Is demonstrable impact of positive working alliances on outcomes necessary to prioritize the quality of consumer-staff relationships in mental health services? If therapeutic relationships are central to consumers' experience in treatment, would addressing the identified obstacles and potential solutions take a central place in services research and assessment? The well-recognized barriers to improved consumer-provider relationships include large case loads, administrative and documentation demands, staff turnover, and insufficient resources for providing smaller case loads, adequate salaries, and administrative assistance. These constraints, however, are seldom considered in assessments of responsiveness and mutuality in consumer-provider relationships.

Shared Decision Making The foundations of shared decision making, another useful framework for examining the process of consumer-provider relationships, are similar to the principles of autonomy, choice, deliberation, and collaboration discussed above.[62] Drake et al[63] introduced an issue of the *Psychiatric Rehabilitation Journal* devoted to shared decision making with a valuable discussion about the meaning and mechanisms of person-centered care in mental health, and we point the reader to that work.

Curtis et al[64] reviewed the components, background, evidence base, and promise of shared decision making, identifying three essential stages of the process: "(1) information and preparation for making a decision; (2) the interactive process of discussing and generating a shared decision; and (3) systematic opportunities to review and revise decisions after they are made" (p. 15). In summarizing their review of evidence, they note that (1) implementing shared decision making in mental health services will require taking into account the context of decisional capacity precedents and power; (2) information is lacking on effective and culturally specific clinical communication strategies; (3) research should focus separately on each step in the shared decision-making process; and (4) the long-term, episodic, and multidimensional nature of consumer-provider interactions require testing and adaptation of extant linear shared decision-making techniques and technologies (p. 19).

As a matter of mental health policy and practice, SAMHSA has given substantial attention to shared decision making in mental health services, including stakeholder conferences and commissioned papers to examine research, implementation, and training. This initiative is consistent with research suggesting that people with serious mental illnesses have stronger preferences for shared decision making than primary care patients, and that among this population, those with more negative views of medications and those who are younger want more participation.[65]

Implementing effective shared decision-making practices in service settings is challenging but feasible. Thompson[66] studied patient involvement and participation in medical settings using focus group interviews and workshops. Participation is considered to be a joint venture, codetermined by patients and professionals and based on reciprocal relationships developed through dialogue and shared decision making. Patient participation, he observed, "requires a narrowing of the information/competence gap between professional and patient, with some surrendering of power by the professional which conveys benefit to the patient, even if there is no consensus" (p. 1299). In a review of randomized controlled trials (RCTs) of interventions to train physicians and nurses to improve patient centeredness in general medical settings, Lewin et al[67] found most studies to show significant improvements in patient centeredness. However, the connection between decision-making practices and health outcomes was not examined in these studies.

The role of technology in shared decision making is growing rapidly, as communication technologies expand the array of mechanisms for involving consumers in mental health care decisions.[68,69] Mobile phone and web-based interventions for symptom management, psychoeducation, and engagement with clinicians show promise in feasibility and in improving outcomes. Deegan[70] developed an innovative software program to improve shared decision making related to medications, in part based on her own personal growth from a passive recipient of prescribed medication to a recovering, more hopeful person who uses medication as part of her chosen self-management. The software program consists of an interactive prephysician visit questionnaire with optional informational videos. A one-page report is produced from the consumer's answers and becomes the basis for discussion with the prescriber. The program has been implemented in a number of clinical settings and is undergoing process and outcome assessment. To date, no results are available.

Summary and Implications The quality of consumer-provider relationships is perhaps one of the best documented influences on assessments of care and outcomes and the least attended to in implementation, intervention development and testing, and reform of system-level factors that impede such relationships. It is clear that consumers prefer high-quality relationships, relationships, and that quality shapes the user's experience of treatment. In order to implement practices that move from "adherence to self-determination"[62] and thereby improve mental health services, research on emerging models and mechanisms in these areas is clearly needed.

Coercion in Services and Treatment

> "We wonder how a person can be considered a user (or consumer) of services which are imposed on them. How can restraint, seclusion and forced medication or electro-convulsive therapy be understood as 'mental health services'?"[71(p216)]

Involuntary and/or coerced treatment in inpatient and outpatient settings is a highly contested issue among consumers and providers, policy makers, and often families and carers. Many consumers consider coerced treatment, whether explicit or tacit, to be the most important barrier to collaborative, effective services and treatment, as well as a source of harm and abuse.[71–75] As with other dimensions of consumer preference for services, however, opinions and experiences regarding the use of coercion vary. Involuntary treatment can be a healing, positive experience for a consumer who is catatonic or suffering from psychosis or delusions. Consumers with these symptoms may be unable to make informed choices about treatment but may desperately need help. Compassionate, caring providers can provide this help with dignity and respect. As one reviewer of this document stated, "Involuntary treatment has saved my life."

Prinsen and van Delden[74(p70)] reviewed the ethical quandaries posed by coercive treatment, including seclusion and restraint, and concluded that "we can neither rule out nor accept coercive measures relying on autonomy or dignitarian grounds alone. We do need to know whether coercive measures are beneficent to complete the argument, and therefore research is necessary. For as long there is no evidence for positive effects of seclusion, the precaution principle of 'primum non nocere' [first, do no harm] should guide our actions." Clinicians and mental health providers also have concerns about coercion in treatment, including disruptions to relationships with patients, pressure from family members who either want or contest the use of coercion or involuntary hospitalization, and the conflict between their roles as agents of the state and patient advocates.[76]

Research on the outcomes of coerced treatment has yielded mixed results, ranging from lack of efficacy to increased use of services and fewer hospitalizations.[77,78] Kisely et al[79(p19)] reviewed the evidence on the outcomes and efficacy of compulsory outpatient treatment, concluding that "community treatment orders may not be an effective alternative to standard care. It appears that compulsory community treatment results in no significant difference in service use, social functioning or QOL compared with standard care. There is currently no evidence of cost effectiveness". That said, it is important to consider the criteria by which effectiveness is assessed. Is the standard to provide demonstrable benefit, or to do no or minimal harm? The latter is supported in some research[78,80] but is contested by other findings[81,82] and by some consumers,[71] including the National Coalition of Mental Health and Consumer/Survivor Organizations.[83] Assessing the demonstration of benefit is a pressing need given the gaps in the evidence and the widespread implementation of outpatient commitment statutes worldwide. For example, the German Federal Court ruled on June

20, 2012, that there was no constitutional basis for involuntary psychiatric treatment among the general population, and it specified the steps required for nonconsensual treatment among forensic patients.[84,85] Such decisions, largely statutory and political in nature, require good data on the effectiveness of coerced care.

The European Evaluation of Coercion in Psychiatry and Harmonization of Best Clinical Practice (EUNOMIA) project is the largest study to date of the outcomes of coercion in psychiatric treatment. The study followed 3 090 individuals from 11 European countries who had experienced some form of coerced hospital admissions.[86] The individuals were classified as coerced involuntary, noncoerced involuntary, and coerced voluntary patients. Initial findings 1 and 3 months postdischarge found significant improvements in primary psychiatric symptoms. The group of individuals who were voluntary but coerced, however, showed less improvement than the other groups. The authors conclude that when coercion is informal rather than done through transparent legal procedures, the subjective experience of coercion may have a particularly negative influence on treatment motivation, therapeutic relationships, and outcomes. These findings echo those of Phelan et al[77] and Link et al[81] regarding the potency of nuanced forms of coercion and stigmatization. The MacArthur Coercion Study provides additional details about the coercion-related experiences of individuals pressured to enter the hospital or involuntarily admitted, finding that such experiences are associated with variations in the presence of "procedural justice,"[87] defined as having a voice in the process and being treated by family and clinical staff with respect, concern, and good faith.

Coercion and Medication Adherence Medication adherence, as a primary goal of community treatment orders or outpatient commitments and involuntary hospitalization,[88] is directly relevant to the prevalence and impact of coercive mental health care. Haynes et al[89] considered trials of ways to help people follow prescriptions across several clinical conditions. Counseling, written information, and personal phone calls were found to be helpful for short-term drug treatments, while in long-term treatments, no simple intervention—and only some complex ones—led to improvements in health outcomes. Complex interventions included combinations of more convenient care, information, counseling, reminders, self-monitoring, reinforcement, family therapy, psychological therapy, mailed communications, crisis intervention, and manual telephone follow-up. Even with the most effective methods for long-term treatments, improvements in drug use or health were not large. Interestingly, several of these studies informed people about adverse effects of their medications, with no resulting effects on their use.

However, the side effects of medications are of significant concern to consumers and prescribers. Pseudo-Parkinsonism, dystonias, akinesia, akathesia, and flat facial expression caused by conventional antipsychotic medications have been replaced with metabolic and cardiovascular adverse effects accompanying atypical antipsychotics.[90,91] Seeman[92] pointed out that younger individuals may be particularly concerned about the loss of attractiveness associated with weight gain. Rosenheck et al[93] found that recovery orientation among service users (compared to medical orientation) was associated with better functioning, fewer symptoms, and less focus on reducing medication side effects. The authors conclude that recovery models and medical models should not be seen as being in opposition to one another.

Despite ongoing efforts by researchers and professional psychiatric groups to reduce polypharmacy and use lowest dose guidelines, progress is slow.[94] Various forms of leverage and strong persuasion to take medications are commonplace in mental health services[95–97] and continue to pose ethical, legal, and therapeutic challenges. While involuntary medication orders in hospital and community settings are subject to judicial review, less obvious and arguably more pervasive coercive pressures are not. Recovery-promoting practices and shared decision making in medication prescribing lag behind other types of interventions and deserve additional intervention research.

Coercion Among Justice-Involved Consumers In view of the high prevalence of diagnosed or diagnosable serious mental illnesses in the prison population,[98] we must consider the use of coercion in this setting, including in jail diversion programs and among parolees whose conditions for release include adherence to mental health treatment. Jail diversion programs for people with serious mental illnesses are increasingly popular, yet the evidence of their effectiveness is restricted to a small number of completed studies. At issue is whether jail diversion participants feel coerced into mental health treatment, and whether feeling coerced influences their treatment outcomes. In a study of 900 jail diversion participants in 13 sites, Cusack et al[99] found that 36% of the sample felt coerced or moderately coerced to accept jail diversion, and 45% felt coerced or moderately coerced to receive mental health services. Considering parolees with mandated mental health treatment, Skeem and Louden[100] reviewed published and unpublished research between 1975 and 2005 and found that specialty parole supervision was associated with better linkage to mental health services. The authors did not assess coercion, however. While jail diversion and mental health treatment as conditions of parole are likely to be experienced as coercive, we lack sufficient evidence to determine how to enhance services for these significant populations. Interestingly, consistent with the MacArthur and EUNOMIA projects' results and Skeem and Louden's findings[100] regarding better outcomes for individuals who experienced transparent coercion, Farabee et al[101] found that the criminal justice system could serve as a link to treatment rather than solely as a source of coercion for those who would not seek services on their own.

Seclusion and Restraint Like involuntary inpatient and outpatient treatment, seclusion and restraint in inpatient and emergency settings are controversial forms of coercion that consumers find especially traumatic.[102] The ethics of these practices have been questioned, as has their legality, therapeutic value, and effectiveness.[74,103] Muralidharan and Fenton[104] reviewed the effectiveness of nonpharmacological forms of containment—including special observation, locked units and rooms, deescalation, and behavioral contracts—and concluded that there was insufficient evidence to support these practices. Prinsen and van Delden[74(p72)] conclude: "It is very hard to argue that seclusion is the appropriate measure to control these circumstances [violence and aggression] when there are no data to support this."

In response to concerns about these practices, various attempts have been made to reduce their use. Schacht[105] described the efforts of the National Association of State Mental Health Program Directors (NASMHPD) to monitor and reduce the use of seclusion and restraint in psychiatric treatment. Over a 4-year period from 2001 to 2005, 150 US hospitals monitored the use of physical restraint and seclusion. Over that period, and in conjunction with training in alternate deescalation and aggression control strategies, hours of seclusion decreased 36% and hours of restraint declined by 46%. The number of service users secluded declined by 26% and the number restrained decreased by 12%. The time of seclusion, however, remained at approximately 30 minutes per 1 000 inpatient hours, and time in restraint about 45 minutes. Administrative and staffing changes, specifically increases in the ratio of staff to service users, have also been shown to reduce the use of seclusion and restraint. Donat[106–108] found that changes at these levels reduced use by up to 75%.

The scarcity of research on the effectiveness and outcomes of seclusion and restraint procedures, and the continued use of such practices in the face of successful alternative approaches, justifiably add to consumers' concerns about involuntary and voluntary inpatient treatment. Additional research is needed to explore alternatives to seclusion and restraint, and to examine the effects of these practices on patient-centered outcomes, including engagement in care. In a recent promising study, Borckardt et al[109] developed and tested an engagement model in five psychiatric inpatient units, along with a hospital-wide initiative to improve consumer-staff communication. The engagement model included trauma-informed care training for staff, changes in unit rules and language among staff, involvement of patients in treatment decisions, and improvements to the physical surroundings. The hospital intervention, called AIDET, set a template for staff-patient communication: **A**cknowledge patients, **I**ntroduce yourself, clarify the **D**uration of the contact, **E**xplain the reason for the contact, and **T**hank the patient. The implementation of these practices resulted in a substantial decrease in the use of seclusion and restraint.

Gaps and Limitations in Research on Coercion The evidence base for the effectiveness of coercion is lacking, and the findings from many investigations lead to divergent interpretations. Moreover, the lack of consumer/patient participation in the design, implementation, and assessment of innovative interventions, as well as the conduct of outcomes research, is a major shortcoming of the current evidence base related to coercion.[110] Researchers are just beginning to explore the unintended consequences of the use of coercion, leverage, seclusion, and restraint, and the more widespread tacit and deliberate pressures to comply with providers or accede to treatment other than one's choice. Kontio et al[102] elicited first-person accounts of seclusion and restraint from psychiatric patients that are both alarming and informative. While the EUNOMIA and MacArthur projects have begun to provide needed data, it is crucial that research of this type be launched in collaboration with mental health service users. Russo and Wallcraft[71] asserted that the terminology, definitions, sample selection, measures, analysis strategies, and questions in much coercion-related research represent an incomplete and limited approach to the subject. Future CER on all forms of coercion, seclusion, restraint, and other forms of involuntary treatment will benefit from improving methods and adopting more inclusive concepts and collaborators in the enterprise.

Consumer-Run Services/Consumers as Providers Here we review the evidence on two related but distinct dimensions of patient-centered services: (1) mental health services that are developed by, staffed by, and managed by identified past or present service users/consumers; and (2) past or present service users/consumers as mental health providers within clinical settings or treatment teams, and as employees of an extant agency, program, or clinical setting that is part of the mental health service system.

A recent review of the extent of mental health mutual support, self-help, and consumer-operated programs in the United States identified 7 467 groups overall, with 1 133 consumer-operated services serving over 500 000 members per year.[111] From a research perspective, consumer-directed programs and services are so varied, with such unique locations and arrangements with existing mental health service systems, that it is difficult to produce useful categories and typologies for analysis and comparison. Salzer, as cited in Campbell and Leaver,[112] proposed this distinction: "Consumer-operated services" are planned, managed, and provided by consumers. "Consumer partnership services" are delivered by consumers, but the control of the program is shared with non-consumers. "Consumers as employees" refers to organizations that employ consumers and non-consumers alike" (p. 36).

A number of program description and research reviews have documented the spread and variety of consumer-directed services.[113] Doughty and Tse[114(p263)] reviewed English-language research published after 1980 that compared consumer-led mental health services with traditional mental health services. “Overall,” they concluded, “consumer-led services seemed to report equally positive outcomes for their clients as traditional services, particularly for practical outcomes such as employment, income, education or living arrangements, and in reducing hospitalizations and the cost of services. Results were varied for client satisfaction and recovery, and some negative findings were reported”. As part of a large project involving the Center for Mental Health Services and NASMHPD, Campbell and Leaver[112] reviewed the background and evidence for organized peer support. They described innovative and successful programs, and included resources for technical assistance. Tan, Mowbray, and Foster (add citation below) identified four goals of these services: (1) to provide a safe, supportive community environment; (2) to provide an atmosphere of acceptance; (3) to promote self-worth, dignity, and respect; and (4) to increase knowledge by learning from one another.[115] In a later report, Consumer-Operated Services Evidence Based Practices,[116,117] findings related to patient-centered outcomes were updated and were consistently positive. These reviews found consistency in improved symptoms, coping skills, satisfaction with life, and social networks and support. There are also a number of descriptive, analytic outcome studies on various types of consumer-directed services.[118–220] These findings are generally consistent with those included in the reviews—that is, participants in these services gained in coping and social skills, reported reduced symptoms, and had increased life satisfaction.

The goals and practices of consumer-operated services are often so different from those of traditional programs that comparisons require caution and clarity. Segal et al[121] conducted an RCT to compare outcomes between a board- and staff-run consumer organization and a traditional community mental health agency. Of the primary recovery-related outcome measures studied, social integration, personal empowerment, and self-efficacy improved more in those participants assigned to the mental health agency, while symptoms and measures of hopelessness did not differ between the two. The authors hypothesize that the consumer program’s organizational structure may have been no less hierarchical than that of the traditional agency, posing challenges to the promotion of better patient-centered outcomes. In a related study, Hodges et al[122] explored the relationship between the use of self-help services and professional mental health services among people who used only professional services and those who used both. Participants who used both services reported more satisfaction with professional services than the group that used only professional services. The authors conclude that self-help services facilitate appropriate use of professional services and that the two types of services can work in a complementary manner.

In addition to operating programs, mental health service consumers are increasingly joining the system as providers.[123] There are many variations in these positions, and little is known about individuals who are employed in the system but are not open about their diagnoses. Research on individual outcomes for clients of consumer-providers is in the early stages. In one of the first comparisons of consumers as case managers with nonconsumer providers, Solomon and Draine[124] found equivalent outcomes for the clients of both groups. Solomon[125] described the critical ingredients of peer-provided services as (1) experiential learning, (2) mutual benefit, (3) use of natural supports, (4) voluntary nature of the services, (5) primary control of the service by peer providers, and (6) peers as recovering and sober role models. Van Erp et al[126] added that training, coaching, and supervision are central to peer providers’ performance of their treatment roles. In a unique clinical trial of a peer-based intervention specifically designed for African American and Latino consumers with psychosis, Tondora et al[125] have thus far learned that the peer mentor-patient relationship required more than the allotted 6 months to develop, that there were challenges in defining the expectations and limits of interactions between the two, and that flexibility in roles clouded some of the distinctions between the two intervention arms. Similarly, van Vugt et al[126] investigated the outcomes of an Assertive Community Treatment (ACT) team that included consumer-providers. They found positive associations between consumer/provider presence in the treatment teams and patient functioning, personal recovery needs met, and reduction in time spent homeless, but they also saw an increase in hospital days. Similar to Tondora et al,[127(p477)] they concluded that “consumer-providers are important participants in outpatient teams serving clients with severe mental illnesses, although integrating these providers as part of a team is a slow process.”

In addition to studies of peer performance in clinical roles, other publications have examined the challenges of implementation and sustainability facing consumer-operated programs and the attitudes of mental health providers toward consumer-providers. Sustainability challenges have been primarily financing, credentials, affiliations with other mental health providers, managing member/user information, and organizational stability.[129–131] Studies of attitudes toward and awareness of mental health providers and their willingness to integrate consumer-operated services into the local system of care have shown that although providers believe consumers can provide effective mental health services, they have less confidence in consumer-run programs.[132,133] Providers in nonpublic settings, agencies that hire consumers as providers, and agencies that collaborate with consumer-run programs are more likely to have made referrals to consumer-operated programs. An Australian study of demographic and workforce characteristics and their relationship to acceptance of peer providers found that receptivity and support for consumer involvement in treatment-related activities varied by gender (females more supportive), time in the profession (junior people more receptive), and time in the job (most senior and most junior least receptive).[134]

Gaps and Limitations in Research on Consumer-Run Services and Consumer-Providers There is a growing research literature and evidence base assessing the feasibility, operations, effectiveness, and sustainability of consumer-run and consumer-directed mental health services, and with consumers as providers within extant services and treatment teams.[113] Most publications are single-program descriptive studies. More recent publications of comparative outcomes and RCTs, while few in number, show that such research is challenging but feasible. The enthusiasm for exploring the potential and effectiveness of these various roles for consumers has been both value and evidence based. The Centers for Medicare and Medicaid Services (CMS), SAMHSA, NASMHPD, and consumer organizations have facilitated a great deal of progress in developing research and program implementation tools. Researchers must continue to expand the type and quality of evidence in these areas. Several innovative practices deserve further investigation: Wellness Recovery Action Plans, developed by Mary Ellen Copeland[135]; Peer Mentors/Bridgers;[127] Personal Assistance and Community Existence, from the National Empowerment Center[136]; and Intentional Peer Support, developed by Sherry Mead.[137] As Davidson et al[113(p127)] observed, implementation of peer support in various forms in mental health may be "messy and complicated", but it also represents the magnitude of progress toward reforms that have been sought for centuries.

Consumer Education of Providers A small number of studies have begun to assess consumer-provided education as a means to address, among medical providers, problems of stigma and lack of experience with people who have mental illnesses. For example, Bell et al[138] reported a novel intervention provided by mental health consumer-educators designed to affect the attitudes of pharmacy students. The outcomes measured were social distance, attribution, provision of pharmaceutical services, and stigmatization of people with schizophrenia and severe depression. Compared with the control students, students who received the intervention had decreased social distance scores, more strongly disagreed with statements that demonstrated a negative attitude toward people with mental illness, and more strongly agreed with statements that demonstrated a positive attitude. Other research, however, suggests that such efforts may not be effective. For example, Meehan and Glover[139] described the experiences of 11 consumer-trainers of mental health staff in Australia. The trainers described a sense of tokenism, voyeurism among clinicians, having to give too much of themselves, and a lack of clear expectations about their roles and tasks. The authors concluded that based on these difficult experiences, there is a need for ongoing critical review of the way that consumer-educators are engaged in the education and training of mental health professionals.

Family and Carers: Needs and Preferences. Family members of adults with serious mental illnesses have diverse needs and preferences relating to their ability to support, care for, and advocate for their family member. They also have unique perspectives on consumer needs and preferences that are sometimes at odds with those of other stakeholders and the consumers themselves. The National Alliance on Mental Illness, one of the earliest advocacy organizations in the United States, was created by close family members of people with mental disorders with the goal of improving services and treatment and combating stigma. Over time, family-centered advocacy organizations have exerted substantial influence on treatment modalities and mental health policies and laws, and they have called for resources to promote social integration of people with mental disorders. The Schizophrenia Fellowship, the United Kingdom's leading family advocacy and support organization, included consumers from its inception, while primary consumers have joined with family advocates much more recently in the United States.

While family members of consumers often provide strong emotional support, link consumers with other stakeholders, and serve as the only source of treatment history, researchers must recognize that family/carers represent their own views and experiences. Unless designated as surrogates, they are limited in their ability to speak for or represent consumers' perspectives and needs. As in other arenas of health care, family members/carers and service consumers sometimes disagree on treatment needs and preferences, which are key considerations for patient-centered approaches in both clinical and research contexts. But despite abundant advocacy and support group literature on the views, priorities, and assessments of family members/carers and service users, the US research literature specifically addressing family members' needs and preferences is comparatively scant. The extant research focuses largely on carer burden and barriers to involvement related to privacy regulations; the effects of carer support groups; the effects of providing education and information about psychiatric disorders; the convergences and differences between the views of carers and the individuals for whom they provide care; and the effects of family involvement and interactions on consumers' prognosis and outcomes.

The most abundant research involving family members and carers derives from the study of educational/informational interventions referred to as family psychoeducation. There is considerable evidence that various forms of family psychoeducation are effective for educating carers about psychiatric disorders, providing coping strategies, and decreasing the distress of family members and, to some extent, consumers.[140] This evidence is reviewed below in the discussion of care and service packages. Here we focus on the beliefs, needs, and preferences of family members/carers as they relate to treatment and service provision.

A number of international studies have examined the role of family members of persons with mental illness in terms of their conception of the illness and recovery. In Spain, Canive et al[141] investigated whether a low-cost psychoeducational intervention would decrease family distress and burden. Compared with mothers, fathers were more optimistic throughout the study about the outcome of the illness, became more aware of the social and financial impact of the illness on the family, and reported feeling less annoyed by the service user's behavior at follow-up. While all of the parents acquired a significant amount of knowledge about the illness, no significant score differences were found immediately after the intervention or at follow-up, suggesting that psychoeducation for family members alone does not decrease family distress and burden. These findings also suggest that psychoeducational interventions should consider gender differences and family roles. In Australia, Goodwin and Happel[142,143] found that family members and significant others contribute to the smooth delivery of care and treatment, particularly when they feel respected and are included in communications, but the researchers also observed a lack of discussion regarding carer participation in health care delivery.

Some research has focused on family members from specific ethnic groups. Despite the growing Latino population in the United States, little research has focused on the mental health of Latino caregivers who have a relative with schizophrenia. Up to three-quarters of Latino persons with schizophrenia live with their families, which may deviate from the residential pattern among the broader population of people diagnosed with serious mental illnesses.[144] Magana et al[144] examined the relationship between Latino caregivers' mental health and perceived burden and stigma, and their relationships with caregiver and service user characteristics. The authors found high rates of depressive symptoms among Latino families caring for relatives with schizophrenia and noted that younger Latino caregivers and those with lower levels of education were at highest risk for depression. The authors conclude that interventions for Latino families should include attention to mental health and recovery among family caregivers.

Scheyett et al[145] examined consumers' and family members' understanding of EBPs within the larger context of their mental health service needs and their experiences with the mental health service system. Both groups were supportive of EBPs but had limited knowledge of them. They questioned the context of these proposed practices and expressed concern about treatment fidelity in certain models, with some family members indicating a lack of familiarity with the specifics of some models and a misunderstanding of the goals or purposes of other EBPs. Family members generally viewed the mental health service system as underresourced and unable to provide EBPs to those in need. They voiced concerns that the focus on EBPs would reduce support for the development of new services, particularly community and residential living opportunities for consumers. Both groups noted the need for supporting more productive activity beyond supported employment (SEm) [146] EBPs, such as further employment and education. Unlike consumers, however, the family groups were less concerned with employment as a source of earnings and more interested in consumers being involved in meaningful and structured activities during their days. Medication management was an issue both groups viewed positively with regard to EBPs. Family members, however, were particularly concerned with the short amount of time consumers spent with their psychiatrists and were concerned that medication alone, without other services in place, was insufficient. Family members were particularly concerned with the discrimination their loved ones experienced in the community and in the current mental health system.

Greenberg et al[147] approached their study of family members' contribution to the QOL of consumers with serious mental illnesses from the perspective that most prior research has focused on the negative impact of family member participation on client outcomes. Past research focused on lowering expressed emotion among family members with little attention to the potential benefits that might result from prosocial family processes such as support, warmth, and affection. Greenberg et al[147] examined longitudinal data from aging parents who were caring for an adult child with schizophrenia, finding that the adult children demonstrated higher life satisfaction when their mothers expressed greater warmth and praise and when their mothers reported the quality of their relationship as being close and mutually supportive. The authors noted that a recovery orientation focused on the strengths of adults with mental illness should focus equally on the supportive presence of their families.[147]

Family-based services were reviewed as part of the Schizophrenia Patient Outcomes Research Team.[148] While the studies reviewed were not focused specifically on assessing family needs and preferences, the authors identified ways in which family member involvement facilitates positive outcomes. Recommendations included that people with schizophrenia who have ongoing contact with their families, including relatives and significant others, should be offered a family intervention that lasts at least 6–9 months. Interventions of this duration were found to significantly reduce rates of relapse and rehospitalization. Key elements of effective family interventions included illness education, crisis intervention, emotional support, and training in how to cope with illness symptoms and related problems. Additional benefits of such programs included increased medication adherence, reduced psychiatric symptoms, reduced levels of perceived stress for service users, improved family relationships, and lower levels of burden and distress among caregivers.

Convergence and Divergence of Stakeholder Opinions. Most US research on family needs and preferences has assessed the convergence, or lack thereof, between stakeholder groups in their assessments and preferences for treatment and outcomes. Simon et al[149] examined whether response bias might account for the frequently reported differences between consumers and providers. They found that the rate of response and type of consumer served did not account for the differences, suggesting that these are real divergences that deserve continued attention. Lenert et al[150] studied whether service users, family members, and health care providers valued health outcomes in schizophrenia differently and, if so, to what degree those differences might adversely affect clinical and policy decision making. There were systematic differences in values with respect to the possible range of impairment resulting from schizophrenia, as well as the common side effects associated with medication. Family members of service users generally had values that were more similar to those of service users than those of health professionals. These results emphasize the importance of participation by service users *and* surrogates in clinical decision making and treatment plan development.

Fischer et al[151] explored the extent and nature of agreement on outcome and service priorities among consumers, their providers, and their family members, as well as providers' and family members' awareness of consumers' priorities. Overall, the results from this study indicate that priorities vary widely among these groups. Providers' and family members' awareness of consumers' priorities was limited and more similar to their within-group preferences than to those of consumers. When the consumer had service contact at least once a month with their provider, however, agreement between family member and provider was greater. While providers tended to value control of symptoms, medication management, and case management the most, family members and consumers tended to value social support, housing, and medical and dental services more highly. In another study, Shumway et al[152] compared policy makers' perceptions of treatment for schizophrenia with those of three primary stakeholder groups: people receiving treatment for schizophrenia, their family members, and their mental health care providers. Because family members were included with service users and care providers within the "primary stakeholder" comparison group, it is difficult to differentiate the stance toward treatment outcomes between family members and consumers. Both the policy makers and stakeholders valued improvements in functioning, specifically productive and social activity, more than they valued improvements in symptoms, particularly deficit symptoms and medication side effects. Policy makers viewed side effects of treatment as less important than did primary stakeholders. The authors note that because study participants did not rate the salience of attitudes or beliefs, the data provide little insight into the formation of preferences for schizophrenia outcomes.[152]

To create common ground among these groups, a broad concept of recovery and remission as more than reduction of symptoms alone is needed, along with a much more detailed understanding of the outcomes valued by stakeholders. Karow et al[153] compared family assessments and perceptions of symptom remission to the assessments of psychiatrists who treated persons with schizophrenia. The study included service users with schizophrenia, their family members, and their psychiatrists. Only 18% of the service users, family members, and psychiatrists were in full agreement in how they assessed remission. Service users tended to value subjective well-being as the most important influence on their perception of remission, while clinicians relied on improved symptom scores. For family members, both low symptom severity and good subjective well-being were considered significantly associated with remission.

Cooperation or conflict among caregivers, consumers, and providers is particularly significant during psychiatric crises. Psychiatric advance directives have been proposed as a means for clarifying the wishes of consumers in emergency situations, and for collaboration with caregivers and providers with consumers.[46,62,97] Swanson et al[154] studied perceptions of PADs among service users, clinicians, and family members, finding that few family members reported ever having received information about PADs. Most family members and service users agreed that advance instructions would help people with mental health problems stay well, and consumers with close family relationships were more likely to support appointing a surrogate. The authors suggested that this is consistent with the notion that family members placed themselves in the role of surrogate decision maker and therefore were supportive of a mechanism that could give them more input. Service users and family members generally agreed that PADs are a means of avoiding unwanted treatment, obtaining needed treatment, and empowering consumer choice.[154]

However, while PADs are widely accepted as useful for improving engagement and communication between consumer, provider, and caregiver, the implementation and use of PADs in emergency rooms and other crisis situations remains problematic, particularly because the document may be unavailable or overridden. Swanson et al[154] examined similarities and differences among families, service users, and clinicians in their attitudes toward, experience with, and understanding of PADs. The study found stark contrasts between service user and clinician perspectives on PADs. Only 12.5% of clinicians reported having had a service user with a PAD or a legally authorized surrogate decision maker, although almost all clinicians said they would recommend that a service user do so if the user were given assistance. However, clinicians were much less likely than service users to feel that avoiding unwanted treatment was a reason for writing a PAD. Rather, clinicians' primary reason for supporting PADs was to help service users feel more empowered. Clinicians were much less likely than service users to feel that advanced instruction would help service users stay well, and clinicians were much less likely to view PADs primarily as a means to avoid involuntarily treatment.[154]

Gaps and Limitations in Research on Stakeholder Perspectives Most authors suggest that convergence of family members' needs and preferences with those of consumers and providers contributes to treatment adherence and better outcomes, but it is not sufficiently clear whether or how shared or divergent views among these groups influence treatment outcomes. As stakeholders, family members should be considered as discrete from service users and providers so that these questions can be addressed in research. There also appears to be little work, longitudinal or cross-sectional, that examines the interactive and dynamic role of family members in the service users' care over time or across populations. Research on contemporary perceptions and experiences of providing care and support for persons with serious mental illnesses should also include investigation of family members' desire or ability to participate in care.

While the dynamic interaction between the service user and various stakeholders is important, an essential part of patient-centered care is undoubtedly incorporating family-centered care. As Scheyett et al[145] suggested, however, equal consideration must be given to evidence-based processes (the processes by which services are provided), and recovery outcomes themselves. Families and carers are an essential component of the process and the outcome and should be a feature of research in these domains. The varying roles of family members/carers include sources of social support, advocates, participants or surrogates in the advance directives of the service user, and liaisons in navigating the various systems of care. On the other hand, they can exert a negative influence by obstructing the individual in obtaining services or simply by failing to offer support. Research addressing how to facilitate positive involvement of families and carers has the potential to significantly affect patient-centered outcomes.

Research into ascertaining, measuring, and capitalizing on the convergence of stakeholder and consumer needs and preferences should continue. Interventions for families, such as psychoeducation, and innovative approaches such as peer guides and coaching[155] require more research, particularly concerning implementation and financing.[156] These interventions also require a method for monitoring progress and evaluating the various types of outcomes people come to prioritize. Clinicians and providers would benefit from more training and education in collaborating with families and facilitating family participation in service user care. Due to the demographic diversity in the United States and the structure of the economic and health care systems, we suggest that future research also attempt to parse out the various cross-cultural and socioeconomic factors that impact policy makers, consumers, and families. Finally, the gaps between family and consumer perceptions of needs and preferences should continue to be examined, as should methods for increasing convergence in such perceptions. The current divide regarding the criteria for involuntary treatment is an especially important area for investigation.

Providers: Needs and Preferences as Part of a Patient-Centered Model of Care for Adults With Serious Mental Illnesses. As a stakeholder group, "providers" encompasses a wide spectrum of health care professionals. Within a patient-centered context, a provider can be any person (paid or unpaid) and any organization that participates in the provision of care or services to people with serious mental illnesses. Roles include psychiatrists, nurses, case managers, social workers, peer mentors, rehabilitation specialists, psychotherapists, and others. While a patient-centered approach prioritizes the values and goals of the consumer, providers have their own needs and preferences. In addition, the practices of those professionals are influenced by organizational and fiscal conditions.

This section reviews literature that is focused on the perspective of the various providers involved in the care, assessment, and treatment of adults with serious mental illnesses. As with the reviewed research on family members of people with serious mental illnesses, many of these studies are comparative across stakeholder groups (ie, consumer, provider, carer). Another prominent theme in this literature concerns shared decision making between providers and service users and their roles in care provision. In the context of mental health care, the current terms for conceptualizing the nature of the consumer-provider relationship include clinician-patient relationship, therapeutic relationship, working alliance, and engagement. As this relationship is the primary site of service provision, it represents a key source of recovery tools and processes. Thus, understanding these relationships, including the characteristics that either help or hinder treatment efforts, is critical to improving service delivery and patient-centered outcomes.

Several interventions have been launched with providers to promote a patient-centered approach in clinical consultations. None of the studies reviewed by Lewin et al[67] were specific to mental health, and all were published before 1999, but their focus on clinician-patient relationships suggests their relevance in this context. The authors found fairly strong evidence that interventions promoting patient-centered care in clinical consultations led to significant increases in patient-centered consulting, and that training providers in patient-centered approaches may improve service users' satisfaction with care. They found little information, however, about effects of such interventions on the health status outcomes of patients, and none of the studies included interventions with non-physician providers. Intervention trials to improve patients' trust in doctors, reviewed by McKinstry et al,[157] have focused on components such as training physicians in empathy and communication, disclosure of financial incentives in physician practices, and how to provide introductory educational visits to the practice. The results showed either no or non-significant increases in trust associated with the interventions.

Provider Approaches to, and Definitions of, Recovery Among People With Serious Mental Illnesses Recovery encompasses both symptom remission and more functional aspects of service users' well-being, such as cognition, social functioning, and QOL. The term *clinical recovery*, distinct from the way that service users and family members might describe recovery or remission in serious mental illnesses, has emerged from the professional literature as a concept focused on sustained remission and restoration of functioning.[158] When adopting this definition, providers view recovery as something that is invariant across individuals and can be measured at intervals to establish baselines and rates. Nevertheless, viewpoints about recovery among clinicians differ widely, ranging from symptom control and improvements in cognition and social functioning to a wide variety of proxy measures for treatment outcome and markers of recovery, including engagement and medication adherence.[159] Understanding the terms by which providers measure and assess recovery will help us conceptualize how recovery is understood by different stakeholder groups and also how clinicians relate to their patients in providing care.

With respect to a patient-centered approach to recovery and the recovery process, clinicians and researchers have placed further constraints on how these are defined.[160] For example, Slade et al[161] suggested that services and providers that use medication adherence as an indicator of recovery are not, in fact, providing recovery-focused services. In another study, Russinova et al[162] aimed to empirically validate a set of conceptually derived recovery-promoting competencies using the perspectives of mental health consumers, consumer-providers, and providers. In their evaluation of 37 competencies that were hypothesized to enhance clients' hope and empowerment, respondents identified conveying a sense of genuine respect for the client as the most important one. Consumers, providers, and families agreed that the following competencies ranked among the 10 most important: helping clients learn skills for self-management of psychiatric disorders; viewing the client not as an illness or solely as a set of symptoms, but as a person; assisting clients in increasing their sense of self-value and self-acceptance; nonjudgmental listening; and believing in the potential for recovery. Being accessible and the cluster of caring, trusting, understanding, believing, and being nonjudgmental were considered most relevant by the client group. Russinova et al[162] suggested that practitioners can foster recovery by acknowledging each consumer's personhood, promoting hope, focusing on empowerment, and providing help with illness management. In addition, they have developed an instrument to measure providers' recovery-promoting competence and to produce guidelines for operationalizing recovery-related processes among mental health and rehabilitation service providers.[162]

Provider Satisfaction With Work in the Mental Health System The mental health system is plagued by workforce problems such as changes in clinician requirements related to the transition to managed care, lack of adequate reimbursement, and increasing reliance on staff with less training and fewer qualifications.[163] Staff turnover is a significant problem[164] that often results in disruptions in care and inability of organizations to retain staff with key training and experience. Provider work satisfaction is, thus, a topic of great importance, as addressing these problems will be critical to system transformation.

Several exceptionally informative studies of the work of mental health case managers in various settings, operating within differing treatment models, provide a robust evidence base for assessing the pleasures, perils, and promise of this frontline practice.[95,165–168] For example, Tennille et al[168] and Munson et al[167] examined the transformative influence of providing care to consumers with HIV and depression. Mental health case managers in the HIV intervention learned that they knew little about their clients despite working with them for years and that adding clinical care for HIV to their responsibilities helped them to better understand their clients' mental health recovery.

With respect to provider and client satisfaction, Mason et al[49] found that both groups shared most values in common. In particular, systemic and organizational factors led to dissatisfaction for both parties. Providers, who strove to have more time with consumers but struggled with large caseloads and paperwork requirements, noted that the opportunity to help very ill people recover and lead fulfilling lives was an intrinsic motivator in their work. Providers expressed dissatisfaction with other demands on their time, which sometimes left them unable to provide needed services to clients. Other factors affecting providers' job satisfaction included poor salary, not having the time to participate in professional growth opportunities such as additional training, and dealing with increases in paperwork required by the transition to managed care. One clinician noted that most providers had to have a second or even a third job in order to support themselves. Low salaries also contributed to the high level of turnover in the profession—a major contributor to consumer dissatisfaction and reduced continuity of care.

Providers also valued flexibility and autonomy in their jobs, and working with talented coworkers who were committed to helping others.[49] There were some organizational factors, however, that strongly influenced provider satisfaction. Specifically, providers were dissatisfied when agencies issued changes in policies and guidelines for care provision but did not provide adequate training in how to implement those policies. This led practitioners to feel that they appeared incompetent.[49] Not surprisingly, Aarons and Sawitzky[164] found that organizational climate affects staff turnover in mental health agencies. In related work, Morris and Bloom[169] examined how organizational culture and climate in 14 community mental health centers affected consumers' assessments of their physical and mental health, concluding that culture and climate had associations with physical and mental health but not with QOL. They also examined the gap between what consumers wanted and what providers were able to deliver. Consistent with Mason et al,[49] consumers and providers both wanted to spend more time with each other, and system barriers such as paperwork and caseload created a gap.

Amering et al[170] took a unique approach to assessing providers' perceptions of care provision: evaluating their attitudes toward PADs. Nurses and psychiatrists were assessed on their knowledge of advance directives and asked to draft one as if they were patients themselves. Among participating clinicians, 54% knew about PADs, 55% considered them legally appropriate, and 29% considered them inappropriate. Interestingly, 75% of providers rejected certain methods of therapy in their mock PADs; 30% excluded the use of neuroleptic medications, and 46% rejected electroconvulsive therapy. The authors hypothesized that attempting to identify one's own needs and demands as a possible recipient of forced treatment is a fruitful way to form an opinion about the possibilities and limitations of advance directives.[170]

Gaps and Limitations on Provider Perspectives The most significant limitations of the evidence in this area concern the lack of careful investigation and interventions designed to address organizational barriers to provider-patient relationships, provider morale, and provider tenure. This work is needed to inform and implement organizational changes that will improve outcomes and consumer assessments of the recovery-promoting qualities of services and treatment. The organization and financing of mental health delivery has been taken as a given and has not been subjected to sufficient scrutiny, particularly with respect to the ways that financing approaches affect both the mental health workforce and the linkages between those workforce effects and patient-centered outcomes. Research is needed to address unintended consequences for providers and for the development and sustainability of effective and acceptable consumer-provider relationships. For example, Hassan et al[171] noted that practicing psychiatrists must balance the often contradictory demands of practicing medicine (eg, dealing in a neutral, disengaged way with illness) and practicing morality (eg, dealing with people whose behavior is morally proscribed), while others[163] have noted that because mental health workers are responsible for treating people with mental illness, providing mental health care itself has become stigmatized. A great deal more information is needed to fully understand the demands mental health work places on practitioners and the ways in which these demands affect patient-centered outcomes.

Service User and Carer Involvement in System Redesign, Research and Evaluation, and Development of Patient-Centered Outcomes. Collaboration in constructing knowledge and assessing outcomes of treatment and services is central to a patient-centered system of mental health services. In this context, it is important to recognize that the quality of research derives not from the types or social labels of researchers but from their expertise, rigor, and analytic skills. Consumers possess knowledge, skills, and conceptual frameworks that are essential for determining which questions to pose, which methods to use for data collection and analysis, and how to interpret results. For example, developing patient-centered outcome measures and scales needs to be a prominent goal for mental health researchers. To create valid measures, researchers will need to construct these indicators from carefully derived assessments of service users' and other stakeholders' concepts, experiences, and goals. The World Psychiatric Association[172] outlined 10 recommendations for collaborative work between mental health practitioners, service users, and family/carers, stating the following:

> Service users and their families have an important role in advocacy in order to enhance the reputation of mental health expertise and services as well as that of people with a lived experience of mental ill health. In recent years, service users and carers have been involved positively in a range of activities including advocacy for support for research, care and social inclusion, and self-help projects. As service users and family carers typically lack the power to interact equally with professionals and government decision makers, assistance in developing this power is mutually important for them and for the WPA [World Psychiatric Association] and the wider international mental health community. (p. 229)

In assessing the present and future participation of consumers and other stakeholders in the work of evaluation, research, and policy, it is useful to consider the underlying motivations for doing so, most notably the promotion of individual freedom, inclusiveness, and equity.

Collaboration may not lead to uncontested solutions, but the process contributes to further inquiry, adjustment of positions, and improvement in the evidence base as the quality of collaboration improves over time.

It is also useful to distinguish between research that is developed and conducted entirely by consumers and collaborative research in which consumers serve as equal partners in the work or, as is most often the case, serve as consultants and coinvestigators. Participatory research models abound and are often required elements of research applications, but there is little consensus about the nature and extent of involvement that qualifies for participatory processes. Studying the results of these different methods of stakeholder engagement, including individual outcomes, is worthy of research. Rose[111] has written extensively about the complexities of consumer-directed and collaborative research in mental health. She and her colleagues posit that the "central tension" in these endeavors exists between differing paradigms for understanding mental disorders, noting that these different paradigms can lead to differences in assessments of appropriate methodologies for scientific enquiry. To address this problem, Rose and colleagues propose using a multiperspective paradigm and a multimethod approach. They also call for increasing service user involvement is setting research questions, developing interventions and assessments, creating and consolidating structures to develop service user and carer research, and using research designs that are consistent with service user preferences. Work completed by Consumer Quality Initiatives, Inc. represents an excellent example of a consumer-directed and consumer-staffed organization conducting high-quality research on consumer perspectives about mental health service quality.[173,174]

There is widespread agreement that patient-centered and patient-informed assessment differs in focus and methodology from other forms of outcomes research. Qualitative methods play a prominent role in identifying the factors that service users feel should be measured, and they can be used to follow the evolution of methods and measures to continue improving their usefulness across stakeholders. Formative methods should also play a key role in measure development. Similarly, qualitative methods are useful for identifying services that consumers find most valuable. Quantitative measures (eg, based on surveys and medical records) can be developed from these foundational understandings.

A number of studies describe consumer evaluations of mental health services using research methods and various collaborative arrangements, including the development of assessment scales and outcome measures. For example, Oades et al[175] developed a consumer- constructed scale to evaluate mental health service provision; Ochocka and colleagues[175,176] developed a participatory action project involving consumers and professionals; Reeve et al[177] described and analyzed their experiences as consumer-researchers within a community mental health research project; and Love et al[178] developed and implemented a user satisfaction survey in an inner-city community mental health center. Each of these examples adds to the evidence base for the feasibility, challenges, and utility of consumer involvement in service evaluation.

Making Services Work for Consumers,[179] a report from the International Initiative for Mental Health Leadership, provides an extensive catalogue of worldwide programs designed to involve consumers in every aspect of mental health service development and evaluation. While the United States sometimes lags behind Europe and Australia with respect to innovations in this area, the challenges associated with consumer involvement are not confined to the United States. For example, Bennetts et al[180] investigated the mechanisms and challenges of extensive consumer participation in transforming mental health services in Victoria, Australia. They describe an ongoing lack of clarity among all parties regarding the proper extent of consumer participation, even with the general consensus that such participation in the education and training of mental health professionals is essential.

Nilsen et al[181] reviewed methods of consumer involvement in developing health care policy and research, clinical practice guidelines, and patient information materials. Their analysis was confined to RCTs, and it focused on outcome measures such as response rates, elicitation of consumers' views, influence of consumers in decisions about outcomes and resource allocation, assessment of the involvement process or products, and the costs of involvement. Consumer interviewers were found to have a small influence on survey results compared with staff interviewers, and the involvement of consumers in developing informed consent documents had little impact on forms compared with those constructed by investigators.[182–184] Face-to-face and telephone contact was more effective than mailed surveys in engaging consumers in setting community health priorities. Consumer involvement tended to change the types of priorities that were proposed. The authors concluded that it was feasible to conduct trials of the effects of consumer involvement.

Resource Acquisition and Distribution

This section examines how mental health services for people with serious mental illnesses are funded and how various financing structures affect their outcomes. The extensive literature in this area covers topics including national health reforms; state experiments; changes in private sector coverage; and cost shifting and risk sharing between different levels of government, between the public and private sectors, and between systems of care and individuals/families. Some studies compare various financing models, with the aim of reducing unnecessary service utilization and improving individual-level outcomes. This section is organized around the following domains:

1. Costs, expenditures, and financing mechanisms.
2. Parity for insurance coverage and adequacy of mental health benefits.
3. Carve-outs, capitation, and managed behavioral health care.
4. Financing services to promote consumer choice.
5. Financing medications for populations with serious mental illnesses.
6. Reimbursement structures and models for service integration.

This section concludes with a discussion on research gaps, implications for CER and PCOR, and suggestions for key leverage points.

Much of the literature on care financing is policy focused or descriptive, rather than comparative. Policy changes in the 1990s, however—as well as the development of capitated models, carve-outs, managed care for behavioral health, and implementation of parity for mental health benefits—offer interesting opportunities for natural experiments in both the public and private sectors. That said, we could not identify any systematic reviews or meta-analyses addressing financing strategies. Most comparative studies are observational, relying on analyses of Medicaid claims or administrative data, or data from large employers and integrated health systems. Additionally, much of the literature dates from more than 5 years ago, and more recent publications often use or cite data from older studies. The most recent literature addresses recent health care reform initiatives and are thus largely editorial.

Perhaps most important, literature on financing primarily addresses models and outcomes related to service delivery rather than patient-centered outcomes. For example, while the literature will often indicate that financial incentives may affect quality of care, it may not specify which elements of care quality will be affected or whether quality of care refers to the delivery-system level (eg, length of stay or rates of hospitalization) or the patient-outcomes level (eg, health status, functioning, reduced comorbidities, or access to and satisfaction with care). The literature also describes and measures the relationships between various financing models (managed care, capitation under various risk arrangements, fee for service), health care service use (number of visits, hospitalizations, length of stay, repeat visits, emergency department use, medication use and adherence), and costs. However, examinations of the links between financing structures and consumers' experiences of care or patient-centered outcomes appear to be largely absent in this literature. We highlight the distinction between outcomes that are system or service oriented and those that are patient centered, as this represents a significant gap in the literature. Despite these limitations, the literature provides important evidence of the ways that various financing mechanisms address service users' needs.

Financing Complexities. It is difficult to get a full picture of the costs of treating people with serious mental illnesses. About $113 billion was spent on mental health treatment in the United States in 2005, representing about 6% of total health care expenditures.[185] Between 1986 and 2005, there were significant shifts in the distribution of mental health costs across provider type and by payer. While expenditures for specialty mental health care increased from $19.5 million in 1986 to $54.4 million in 2005,[185] the percentage of these expenditures relative to all sources of expenditures dropped from 61.3% to 50% over the same period. This decrease was due primarily to the higher percentage of spending on prescription medications, from 7.4% ($2.4 million) to 26.6% ($30 million). The distribution of expenditures by payer also shifted to private insurance, perhaps owing to parity laws, and to Medicaid, with a corresponding decrease in expenditures by other state and local sources. Of the $113 billion spent on mental health nationwide in 2005, 28% was through Medicaid. Medicaid spending for people with serious mental illnesses accounts for about 10.7% of all expenditures for mental health care.[185] SAMHSA projects that spending for mental health and substance abuse services will increase to $239 billion by 2014, with prescription drugs being the fastest-growing component of spending. Projections are also likely to be significantly affected by the "imminent and serious mental health needs of returning combat veterans" and natural disasters, economic conditions, and shifting political environments.[186]

The literature in this area is extensive but fragmented. For example, Fenton et al[187] compared a residential crisis treatment program with general hospital psychiatric care and found that acute treatment episode cost was $3 046 per person for the residential program compared with $5 549 for hospitalization (1995 dollars). Six-month treatment costs were $19 941 for residential crisis treatment and $25 737 for psychiatric hospital care, demonstrating the cost-effectiveness of this program. In a study of one large employer covering 1.66 million lives through private insurance with a managed behavioral health plan that included behavioral health services, Peele et al[188] found that annual expenditures (based on 1996 claims data) for people with bipolar disorder were $2 470, or 400% higher than for people with other behavioral health disorders. People with bipolar disorder also paid more out-of-pocket costs annually ($538) than people with other behavioral health needs ($232), a discrepancy due in part to higher hospitalization rates. People with bipolar disorder had significantly more admissions for medical concerns than people with other behavioral health disorders. Overall, people with bipolar disorder represented 3.0% of the group with behavioral health claims but accounted for

12.4% of all behavioral health expenditures. The authors conclude that prevention and long-term management of bipolar disorder could potentially reduce hospitalizations and substantially reduce behavioral health expenditures. In another study of a large health maintenance organization (HMO), Simon and Unutzer[189] reported that costs of mental health and substance abuse treatment for people with bipolar disorder were six times higher than for patients with depression, and 20 times higher than for the control group. Of particular note, mental health and substance abuse services accounted for less than half (45%) of all medical costs for patients with bipolar disorder, only 10% for all health costs for patients with depression, and only 5% for the control group. This further suggests that medical costs are a significant portion of overall costs for people with serious mental illnesses.

Gilmer et al[190] demonstrated that full-service partnerships (FSP) that provide housing for people with serious mental illnesses and engage them in treatment increased outpatient costs (measured in 2007 dollars) by $9 180 per person over a 3-year period, but reduced inpatient costs by $6 882 and emergency service costs by $1 721 per person. This study measured changes in housing status, receipt of disability benefits, employment, mental health services use, and costs for adults in San Diego's FSP program and self-reported QOL for FSP and homeless clients receiving services. The reductions in costs for inpatient, emergency, and justice system services offset 82% of FSP program costs. It should be noted that while the FSP did not fully offset all costs, recovery outcomes were significantly improved: the number of days spent in congregate or residential housing situations increased by 99% (from 74 to 174 days) and the number of days spent homeless decreased by 69% (from 191 to 62 days). Additionally, receipt of disability benefits (including Supplemental Social Security Income or Social Security Disability Insurance) increased from 53% to 70%, suggesting that the FSP program significantly improved clients' housing stability and income.

Rothbard et al[191] conducted several studies of care costs for people with serious mental illnesses and HIV, demonstrating that people with both illnesses had the highest annual medical and behavioral health Medicaid treatment expenditures ($20 038 per person, 2008 dollars) compared with people with either serious mental illnesses only ($16 253 per person) or HIV only ($14 714 per person). In a study using New Hampshire Medicare and Medicaid claims data from 1999, Bartels et al[192] estimated average annual per-capita Medicaid and Medicare expenditures for people with schizophrenia compared with people with depression, dementia, and other medical disorders (defined as all other dually eligible individuals who did not have a psychiatric disorder). They found that older adults had the highest per-capita expenditures ($39 154–$43 461), primarily for nursing home care, compared with younger adults with schizophrenia ($25 633 for ages 19–44 and $31 529 for ages 45–64), primarily for outpatient care. They also found that per-capita expenditures for people diagnosed with schizophrenia were $11 304 higher than for people diagnosed with depression and $28 256 higher than for individuals with medical but no psychiatric disorders. The authors concluded that schizophrenia is one of the most expensive disorders across the age span and that expenditures increase with age.

The literature on costs of mental health in prisons is no less varied. A report by the US Department of Justice found that in 1999, 16% of state prisoners reported a history of mental illness.[193] Glied and Frank[194] reported that by 2006, as many as 7% of those with such illnesses may have been incarcerated. Wolff[195] estimated costs of reentry planning and the first year of postrelease services for inmates with mental illness, based on an assumption that about 96 000 inmates would reenter the community with mental health problems in a 1-year period. Extrapolating from a sample of male adult inmates in New Jersey, about 11% of whom had a serious mental illness, costs for mental health treatment were estimated to range from $6 000 per case for basic management in the community to $19 985 for ACT (2003 dollars). Costs for substance abuse treatment were estimated to be $3 894 per individual.[195] In another study, Alemi et al[196] compared the costs of colocating probation and substance abuse treatment ("seamless treatment") when clients select their treatment. Relative costs of treatment were $38.84 per client per day for seamless treatment compared with $21.60 for conventional services. Although the seamless treatment group had lower recidivism, the cost savings did not offset program costs.

An older but important study on the costs of psychiatric drugs in the Iowa prison system demonstrated that overall expenditures for psychiatric drugs increased 28-fold from $7 974 in 1990 to $381 893 in 2000, or from $2.91 to $81.38 per inmate.[193] Use, however, increased only by a factor of five. The study further assessed costs and use by class of drugs. Per-inmate expenditures for antipsychotic drugs increased from $2.15 in 1990 to $19.29 in 2000, while use remained relatively constant, reflecting increased prescribing of atypical antipsychotic medications as first-line treatments. The largest growth was seen in the use and cost of antidepressants. Expenditures for this class of drugs increased by $47.56 per inmate over the 10-year study period (from $2.30 in 1990 to $49.86 in 2000) and accounted for almost two-thirds (62.4%) of the overall increase in expenditures for psychiatric drugs. Per-inmate expenditures for other psychiatric drugs also soared between 1990 and 2000, including mood stabilizers ($55.30 per inmate), and anxiolytics and hypnotics ($61.00). The authors question whether the increased use of psychiatric drugs in prison is accompanied by improved outcomes, a question that remains pertinent today.

A study from the United Kingdom by Barrett and Byford[197] evaluated the costs and benefits of a program for inmates at high risk of serious reoffending due to personality disorder. Provided in stand-alone units in hospitals and prisons, the program uses a range of therapeutic approaches to motivate change and reduce recidivism risk, including cognitive-behavioral and dialectical behavior therapy. Costs were computed over a 25-year period, with total program costs equal to £37 082 per client per year (2005–2006 pounds) compared with £19 408 per client per year in usual care. Although the higher costs of the program were accompanied by lower average rates of serious offenses, the incremental cost of the intervention was not cost-effective. Sensitivity analyses were conducted on level of prison security (high, moderate, and low), conviction rates, program duration (1 year compared with 25 years), and discount rates of 0% and 6%. With the exception of the program being provided in a low-security, low-cost prison, the cost-benefit ratios showed that costs exceeded benefits of reduced serious reoffending.

Funding Streams. Services for people with serious mental illnesses are funded in numerous ways, including Medicaid, Medicare, federal block grant funds, state general assistance funds, employer-based coverage,[198] the Department of Veteran's Affairs, and the Department of Defense for military personnel.[199] Non-health–related funding streams come from the Social Security Administration[200] and the Department of Housing and Urban Development.[201] These institutions provide income-, employment-, and housing-related funds.

There are four important issues related to financing for researchers to consider. First, each funding stream has its own rules governing program eligibility, scope of coverage for services, and use of funds. Even a cursory examination of the continuum of services and their alignment (or lack of thereof) with statutory limitations reveals the complexity of financing services and illuminates why "seamless" care can be so difficult.[198] These circumstances can create challenges for developing and testing alternative funding arrangements. Second, because most health and mental health services for people with serious mental illnesses are financed through Medicaid, a program jointly paid for by federal and state governments, it is critical to understand how state Medicaid programs are structured and how federal and state Medicaid policies are changing under health reform. Third, reimbursement mechanisms can affect the quality of services if they either fail to reimburse for needed services or do reimburse for services that may be harmful if provided in excess. Finally, Medicaid is not run uniformly across the country. Above the basic "floor" that consists of federally required services for federally mandated populations, each state can choose to expand eligibility rules to provide mandated services for optional populations, increase the scope of services beyond federal mandates for eligible populations, and determine which optional populations are eligible for which optional services. Additionally, the federal government allows demonstration projects to test innovative strategies to meet the needs of the state through "waiver" options. Thus, access, quality, and scope of care, as well as the comprehensiveness of service packages that determine individual outcomes, may vary substantially by state.

The complex array of funding mechanisms and state choices present both opportunities and challenges for CER and PCOR. While we can learn much from states' successful experiences and best practices, the primary challenge for researchers is making valid comparisons between financing structures. Moreover, programs are implemented within varying state political and organizational contexts. As a result, for example, people with similar sociodemographic, medical, and mental health characteristics may have different outcomes under programs that appear to be similar. Geographically based financial characteristics may be a key factor to consider in understanding and assessing improvements in outcomes for people with serious mental illnesses.

Costs, Expenditures, and Financing Mechanisms. The literature on costs, expenditures, and macrolevel financing can be classified into three groups. The first group represents a substantial body of literature that describes national trends in the costs and expenditures for mental health services, delineates the shifts in financing from private to public systems, and describes trends in decentralization from federal to state and county systems of care.[198,202–210] These articles are descriptive in nature, typically use existing national or state administrative databases, and tend to be policy focused rather than comparative. Important, this literature is not generally linked to patient-centered outcomes.

The second literature group focuses on the advantages and disincentives of different payment structures and on opportunities for creating and aligning financial incentives to improve quality of care and cost savings.[210–215] These articles focus on changes in service delivery systems, with some attention to developing payment mechanisms to support service integration (eg, how to finance medical homes for individuals with serious mental illnesses). As with the first group, these publications do not typically address patient-centered outcomes except to suggest that the incentives created by various financing strategies may affect quality of care and individual outcomes. Patient outcomes and specific quality improvement targets, however, are not generally articulated.

A third group of articles is more focused on costs and financing for individuals with specific diagnoses, such as schizophrenia, or serious mental illnesses with co-occurring substance-abuse disorders. This literature presents specific cost trends and service use and highlights the need for more research on subpopulations.[192,216] These articles, which also do not specifically address patient-centered outcomes, are oriented toward systems-level analysis and are focused on identifying expenditures and their sources or comparing expenditures across different sources or between different disorders. This literature is not typically oriented toward individual outcomes.

Summary and Implications The current state of macrolevel literature on resource acquisition and distribution is helpful for understanding national and state trends, costs and expenditures, and policy issues related to financing for mental health service systems for people with serious mental illnesses. At this time, however, it is not particularly useful for addressing the effects of different financing or distribution approaches on patient-centered outcomes. Existing studies generally capitalize on administrative data, very little of which includes measures of patient-centered outcomes. This raises key research questions: Given the other goals of financing systems, how might these systems be used to improve patient-centered outcomes? How can we embed patient-centered outcome measures in administrative data to better understand how financing structures affect outcomes for people with serious mental illnesses? Answering these questions will require more research and better models that directly link resource acquisition and distribution policy to specific patient-centered outcomes and experience of care.

Parity for Insurance Coverage and Adequacy of Mental Health Benefits. Prior to 1996, inequities existed between medical and behavioral health care coverage requirements. The Mental Health Parity Act of 1996 prohibited private health plans from placing greater limits on behavioral health services than on medical health services. Despite this mandate, however, consumers continued to experience differential limits on the number of visits and covered days, as well as greater out-of-pocket expenses for behavioral health services compared with medical care.[217] In response, the federal government passed the Mental Health Parity and Addiction Equity Act, which was implemented in 2010.[217]

Several studies have demonstrated that the Mental Health Parity and Addiction Equity Act increased coverage for behavioral health services and use of such services. It also reduced out-of-pocket expenses for consumers covered under both private and public health plans,[218–220] including the Federal Employee Health Benefits Program (FEHBP).[221] Several studies have addressed service use following parity.[218,219,221–225] Comparisons of FEHBP and non-FEHBP plans indicated no significant differences in inpatient care[226] or substance abuse treatment services.[227] Rates of initiation and engagement for substance abuse services, however, were greater within FEHBP plans than comparison plans,[227] and use of mental health services and psychiatric medications declined in non-FEHBP plans.[226] The latter finding raised concerns about access and quality of care in non-FEHBP plans. The FEHBP plans, which were under a 2001 presidential directive to increase parity for a wide range of mental and behavioral health benefits, were also seen as significantly more likely than private plans to implement a "carve-out" contract to better manage the costs of behavioral health services.[228] The use of carve-outs (see below) is believed to explain the lack of increase in total spending following implementation of parity requirements.[221,227,228] It should also be noted that because care for most people with serious mental illnesses is publicly financed, enhancing parity in the private sector may not be the most effective financing tool to improve patient-centered outcomes for this population, even though it may increase access and improve outcomes for people with milder or intermittent mental illness.

Summary and Implications The literature on parity suggests that it (1) creates incentives for insurance plans to use managed behavioral health care contracts to control costs and utilization; (2) generally does not increase overall costs to plans and may result in decreased expenditures, particularly if carve-outs are initiated and both medical and behavioral health services are managed similarly; (3) reduces out-of-pocket costs for consumers; and (4) does not threaten access to mental health services. In fact, parity may lead to modest improvements in the quality of mental health and substance abuse services. Additionally, the literature is vague on the effect of parity on important patient-centered outcomes and service users' experience of care, particularly initiation and engagement, prior authorization requirements, wait times for treatment, improvements in health status, and continuity and satisfaction with care. Because care for a majority of people with serious mental illnesses is financed through the public sector, parity may not be the most effective financing tool for improving patient-centered outcomes for people with serious mental illnesses.

Carve-Outs, Capitation, and Managed Behavioral Health Care. There is a significant, albeit dated, body of literature on managed behavioral health carve-outs (MBHCOs), capitation, and the development of managed care for behavioral health care services.

Carve-outs were developed in the mid-1990s in both the public and private sectors to address rising costs for inpatient services, contain risk, and improve efficiency and access to care.[229] Carve-outs are based on the economic principles of economies of specialization and economics of scale, price negotiation, and selection.[230] While carve-outs can create economics of scale for specialized services, separating mental health from other health services with respect to payment and management also fragments care delivery, and it creates incentives that further dissociate primary care providers from clients needing mental health services.

Contractual Arrangements Frank and Glied[205] reported that carve-outs in the private sector create a variety of financial incentives for specialty care referral and medication prescribing, create disincentives for treatment and follow-up care for people with serious mental illnesses because of inadequate reimbursement, and move medical decision making away from using EBPs.[205] These results suggest that the details of a carve-out contract are important for identifying which incentives and disincentives are in play and, more importantly, how the incentive structure is likely to affect individual outcomes. Similarly, several studies highlight a wide variation in organizational and contractual arrangements among state Medicaid carve-outs for behavioral health services.

Aspects of contracting that seem particularly important to individual-level outcomes include risk-sharing arrangements (eg, out-of-pocket costs to consumers, possibly reducing access to care) and provider networks (eg, access to specialty care for people with serious mental illnesses). Administrative readiness, the procurement process, previous experience providing services in a capitated model, and program monitoring and evaluation are more likely to indirectly affect service user outcomes by creating either stronger or weaker organizational models of care that affect access to and quality of care.[231–233] In most studies assessing carve-outs, however, models and data for linking contract components to patient-centered outcomes are missing.[232]

States have had varying degrees of success with carve-outs. New Mexico's experience capitating Medicaid services through a single for-profit private corporation resulted in significant administrative problems, including complex documentation requirements, increased administrative burden on providers, inadequate administrative oversight, insufficient attention to the rural safety net, payment problems, and high turnover among providers.[234–236] Similarly, Florida learned that even when program implementation successfully creates a fully integrated mental health delivery system with financial and administrative mechanisms that support a shared clinical model, there remain concerns about access to care, stability, efficiency, and shifting of risk from the public sector downstream to private organizations with limited oversight or support.[237] These and other real-world experiments suggest that variation in contract details can alter the MBHCO's ability to achieve financial viability, serve its target populations, and improve individual outcomes.[238] CER and PCOR projects examining alternative financing and distribution approaches resulting from the ACA and recent Medicaid waivers could shed light on which contractual elements are most likely to result in improved patient-centered outcomes.

Costs and Utilization Behavioral health carve-outs have been widely reported to result in cost reductions in both private-sector MBHCOs[205,230,231,239–244] and state Medicaid programs.[232,245–248] Grieve et al[246] further concluded that in Colorado, the capitated model with a for-profit component (the "joint venture" model) was more cost-effective than the not-for-profit capitated or fee-for service models. Carve-outs have also been observed to reduce overall behavioral health service use in both public[232] and private[249] arenas. They reduce use of psychiatric emergency services,[250] shift use from inpatient care to outpatient and community-based services,[247,250] reduce the duration and intensity of treatment,[248] increase crisis referrals, and increase the use of second-generation antipsychotic medications.[250] Significantly, studies have demonstrated that utilization tends to (1) decrease for services for which the MBHCO is financially at risk and (2) increase or show no change for services for which the MBHCO is not financially at risk.[203,251] What is not clear is whether these system changes affect patient-centered outcomes or quality of care. This is an important question that could be addressed by CER and patient-centered outcome researchers.

It is also important to understand changes in societal or distributional costs resulting from different financing arrangements. In a series of recent publications, researchers compared treatment and societal costs among three risk-based financing strategies in Florida: a large Medicaid HMO with a fully integrated premium covering general medical, mental health, and pharmacy services; Medicaid fee for service; and a private managed care organization with a fee-for-service behavioral health carve-out. In the first study, the authors found that the unadjusted total treatment costs for people enrolled in the HMO were 50% lower than costs for fee-for-service enrollees.[252] The difference was largely explained by informal utilization practices that limited access to clozapine. They also found little difference in the costs of physical health services by financial risk arrangement. In a follow-up study, however, Shern et al[253] found that although the Medicaid managed care plan resulted in cost savings, the savings were either diminished or eliminated when including all societal costs, including private and family expenditures. In particular, people in Medicaid managed care plans appeared to receive significantly more informal caregiving than people in fee-for-service plans. The authors pointed out that most budgets are determined within an agency or organization, with little concern over the distributional effects to other sectors. This is problematic, as people with serious mental illnesses may require multiple services across sectors and payers. It is, thus, essential to understand the distributional and societal cost impact of different risk-based financing strategies.[253]

Several studies have also highlighted differences in utilization among subpopulations being served in MBHCOs. For example, comparing two captitation models and a fee-for-service model in Colorado's Medicaid program, Kaskie et al[248] found that utilization among older beneficiaries decreased more in the "joint-venture" capitated model, in which a for-profit organization collaborated with a community mental health agency, than in the nonprofit public capitated model. This was consistent with the organizations' different management philosophies, but it did not hold true for younger beneficiaries. Costs were also reported to be higher for older clients. Among welfare beneficiaries in Massachusetts, Norton et al[247] found a decrease in total per-person expenditures, a concurrent shift from inpatient to outpatient care, and no evidence of cost shifting to the medical sector. However, these findings contradicted what was found in a sample of Medicaid beneficiaries eligible due to a mental disability, suggesting important differences between welfare and Social Security Income recipients receiving mental and substance abuse services through the same program.[247] These findings suggest that more research is needed addressing differential effects and relationships of payment structures to patient-centered outcomes on priority subpopulations. In particular, more information is needed regarding the effects of different payment structures on individuals in rural and other underserved areas lacking access to mental health specialists, members of minority groups, clients with low literacy, those with different diagnoses, and clients with major medical comorbidities.

Individual-Level Outcomes The effect of carve-outs on individual outcomes varies significantly from study to study. Results remain unclear,[254] are missing from analyses altogether,[247,248] or are mixed.[230,249,251,255] Cohen and Bloom[256] reported that continuity of care, an important aspect of care from the service user's perspective, was greater in capitated models than in a traditional fee-for-service model. Similarly, Cuffel et al[232] found no significant differences in outcomes among different models of capitation but did find a difference between capitation and fee-for-service models. Ridgely et al[237] voiced concerns about access, quality, and outcomes but did not elaborate on underlying causes. Typical of this literature, the aspects of carve-outs that are most likely to affect outcomes (eg, risk-sharing arrangements, provider networks, prior authorization, and service limits) were not made explicit. To date, few studies have addressed the underlying question of how financing structures relate to patient-centered outcomes and recovery among people with serious mental illnesses, in part because the data necessary to address these questions are not easily available from claims or administrative data. Key questions remain: Under what conditions does a shift from inpatient to outpatient care improve patient-centered outcomes? Which settings are preferred by service users and under what circumstances?

Summary and Implications Capitation, carve-outs, and managed care have become important tools for managing costs and utilization in behavioral health care. Overall, carve-outs for behavioral health services have resulted in cost savings and reductions in inpatient hospital use and a shift in utilization from inpatient to outpatient settings across sectors and over time. The literature clearly shows that carve-outs can create powerful and disparate incentives as well as disincentives, depending on how risk and contractual elements are handled. Services for which an MBHCO is not at risk will tend to increase while services that do present risk will tend to decrease. Carve-outs also have the potential to increase service delivery fragmentation, create issues in coordination and medication use, and affect service user health status and other outcomes of interest to consumers. Two important questions remain: What are the specific organizational and contractual/risk-sharing aspects of carve-outs that improve outcomes for people with serious mental illnesses, and what patient-centered outcomes are affected?

Studies of carve-outs also demonstrate that a broad-based analysis may mask important differences among subpopulations and that contractual arrangements are critical in understanding how carve-outs affect individual outcomes. Furthermore, outcomes among studies on carve-outs tend to focus more on service delivery issues and, as a result, do not fully or adequately address patient-centered outcomes. Discrete and subgroup analyses remain important, as does research reflecting the importance of outcomes of concern to consumers, something which is currently missing from this body of literature. To address this issue, better measures of patient-centered outcomes need to be embedded within administrative and claims databases for use by researchers assessing different financing mechanisms.

Bundled Payments. Bundled payments have been described as payments that are based on the average costs of care and made to a provider organization to cover all expenses associated with a discrete illness episode. Under a bundled payment mechanism, providers are at risk for overutilization and outliers.[257] CMS began experimenting with bundled payments for coronary bypass in the late 1990s, which resulted in $17 million in savings in the first 27 months of the program.[258] CMS is currently considering implementing bundled payments for hospitals and common inpatient services. More recently, bundled payments have been incorporated in cancer treatment,[257] end-stage renal disease,[259] and, in the Netherlands, diabetes care, chronic obstructive pulmonary disease care, and vascular risk management.[260]

Birkmeyer et al[261] and Miller et al[262] found significant variation in the costs of surgical procedures and post-care management across the country and across different types of providers under Medicare. A preliminary evaluation of bundled payments in the Netherlands showed improved organization and coordination of care, better collaboration among health care providers, and better adherence to care protocols. However, it also appeared that bundled payments resulted in large price variations that could not be fully explained by differences in services, as well as increased administrative burden due to outdated technology.[260] Similarly, Draper[263] reported that management of bundled payments would benefit from improved clinical information technology tools. He cited a long list of organizational and management efficiency tools and processes as important factors in the successful application of bundled payments.

Any application of bundled payments to the delivery and management of services for people with serious mental illnesses would need to account for (1) the inherent variation in service needs by demographic and clinical factors, (2) the potentially wide and uncertain variation in service needs over time within an illness episode, (3) the need for services that are typically outside the medical sector, (4) adequacy of payment relative to risk, and (5) the "patient centeredness" of payment and the potential to pay for services that include a wider range of providers, such as peer providers. Bundled payments offer the potential to align provider incentives to promote system efficiencies for mental and behavioral health services. At the same time, it will be important to ensure that realized efficiencies and provider incentives are evaluated against patient-centered outcomes, not cost savings alone.

Financing Services to Promote Consumer Choice. Promoting consumer choice is at the heart of patient-centered care. The discussion above makes clear that financing methods and structures can exert a powerful influence on how care is delivered and received. Dewa et al[234] compared consumer choice under three financing structures: fee for service, a capitated prospective payment model, and a blended model (capitation with elements of fee for service). These comparisons showed that each financing structure embodied a different set of incentives, with the fee-for-service model providing the fewest incentives for encouraging shared decision making in care. The authors suggest that changes to the reimbursement system are needed to encourage the shared-care practice model. They also concluded that changes in financing alone are not sufficient to promote the shared-care model.[234]

Self-directed care programs are designed to promote consumer choice and patient engagement in their own recovery by giving them control over public funds to purchase services and supports.[264,265] The federal Office of the Assistant Secretary for Program Evaluation recently commissioned a systematic review of consumer-directed care, which should be available in the near future (R. G. Frank, PhD, personal communication, May 23, 2012). Results from an earlier pilot program on self-directed care found positive outcomes for participants, including spending less time in inpatient and justice settings and spending almost half of the funds on individual treatment.[266] In 2003, CMS created the "Money Follows the Person" (MFP) program with the goal of creating a flexible financing mechanism that would allow people with long-term needs and high use of institutional care to receive appropriate care in the community or at home. The program allowed funds to "move" with people as their needs and preferences for setting change. Given that people with serious mental illnesses experience changes in health status and move in and out of institutional care, this model may hold promise. CMS awarded $6.5 million to nine states—California, Idaho, Maine, Michigan, Nevada, Pennsylvania, Texas, Washington, and Wisconsin—resulting in numerous initiatives. Additionally, CMS increased federal matching funds for home- and community-based services to promote more "rebalancing" of services at the state level. Because of the ways in which funding operates at the state level, the MFP essentially required states to enact legislation that would allow transfer of money between funding streams—a difficult task. States have experienced varying degrees of success with this program. For example, Alakeson[265] identified three main barriers to explain lack of program development: the absence of a strong evidence base to support the effectiveness of self-directed care for serious mental illness, uncertainty over the appropriate scope of self-directed care, and the absence of sustainable funding sources. MFP programs were set to expire in 2011 but were continued through the ACA for another 5 years. Thirteen states will receive more than $45 million in the first year of the program, and more than $621 million through 2016.[267] These efforts provide natural experiments ripe for comparisons.

The federal government also instituted a "Cash and Counseling Demonstration and Evaluation" program that expanded opportunities through Medicaid by funding demonstration projects that shifted the funding model to one in which program participants—all of whom were disabled, including those with serious mental illnesses—were free to choose the types and amounts of services and supports they believed were best able to meet their disability needs.[268] Research from the programs in New Jersey, Arkansas, and Florida suggests that consumers' control over personal care greatly improves their satisfaction with care arrangements and their outlook on life,[269,270] and that it is a viable model for people with serious mental illnesses.[271]

Summary and Implications Consumer-directed care is an important component of patient-centered care and can promote engagement and satisfaction among service users. Financing mechanisms have been successfully developed to achieve consumer-directed care and appear to be viable for people with serious mental illnesses. Further comparisons are needed to provide a clear understanding of the effects of different approaches to financing consumer-directed care on patient-centered outcomes.

Medication Financing. Costs for prescription medication have soared in the past 20 years, increasing from $10 billion in 1998 to $25 billion in 2008.[185] For people with serious mental illnesses, two issues regarding financing for prescription drugs are of particular importance: the increasing use of carve-outs to control costs and service utilization, and the recent development of the prescription drug benefit under Medicare Part D. As noted above, MBHCOs and other types of capitated plans are typically not at risk for the costs of prescription drugs. Comparisons of these different approaches have produced conflicting results. Several studies report that, compared with traditional fee-for-service plans, MBHCOs in state Medicaid programs have either decreased costs for or increased use of psychiatric medications.[243,255,272] In contrast, other studies have found that use, continuity, or adherence was reduced under carve-out arrangements,[272,273] or that there were no significant differences between carve-out plans and traditional fee-for-service plans for medication use.[251] More research is needed to determine the effects of different arrangements on individual outcomes and to identify the factors producing these differential results.[243]

The Medicare Modernization Act of 2003 shifted medication coverage from Medicaid to Medicare for people who were eligible for both programs.[274] More recently, Medicare was expanded to create prescription drug coverage for all Medicare beneficiaries, known as the Part D program. This change significantly increased coverage and reduced out-of-pocket costs for consumers, but the private sector responded with a complex array of programs and administrative and management structures to take advantage of this new opportunity. Concerns about the Part D program included disruption in service, confusion about enrollment, increased costs, and cost shifting. A number of researchers hypothesized that because of the complexity of the program, some dually eligible beneficiaries would experience disruptions in or barriers to access to medications, in addition to other treatment gaps.[254,274–278] Although dually eligible beneficiaries were automatically enrolled in Part D to mitigate these concerns, Huskamp et al[279] reported that emergency department visits were significantly higher for those who experienced access problems under Part D, raising questions about its effects on quality of care.[279] Zivin et al,[280] however, found no significant differences in enrollment between beneficiaries with depression and cognitive impairments and those without these difficulties.[280]

Prior Authorization and Cost Sharing Prior authorization policies and cost sharing are two additional tools that have been effectively used to control medication costs.[281–283] Studies in general populations have reported that prior authorization and cost-sharing requirements have reduced access to and continuity of prescription medications,[283,284] increased use of emergency departments,[279] reduced availability and use of medications,[274] and reduced medication adherence.[285] These findings raise concerns about the effects of such approaches on vulnerable individuals with serious mental illnesses, who already experience reduced access and continuity of care and are less likely to adhere to medications.

Summary and Implications The literature on financing for prescription drugs shows variation in access and use for both Medicaid and Medicare clients, highlighting the importance of understanding the details of health plans' administrative and risk-sharing arrangements and the effects of these arrangements. In particular, more information is needed about the effects of elements such as prior authorization and cost-sharing arrangements on clinical and patient-centered outcomes. For the most part, analyses have been limited to assessments of costs and utilization.

Reimbursement Structures and Models for Service Integration. This section addresses how current financial arrangements affect service integration within and between systems of care, and the extent to which they affect patient-centered outcomes. Specific methods and models of service integration and care coordination are discussed more fully elsewhere in this report.

The Need for Service Integration There is widespread agreement that a subset of people with serious mental illnesses require ongoing, coordinated, and multiple interventions to appropriately and adequately address their needs. The array of services include medical care, mental health services, addiction treatment, social services, transitional services for people moving in and out of different levels and systems of care, housing, education, employment, and services related to the justice system. For example, people with serious mental illnesses are more likely to have major physical health and substance-related comorbidities,[286,287] and more likely to use emergency department services, than people who do not have these disorders.[216,250] They are also more likely to be unemployed, to have low income,[195,288] and to have housing issues.[195,289,290] Additionally, people with serious mental illnesses may need different services at different stages of the recovery process.[291,292]

There is also consensus that current financing arrangements have not been organized or adequately funded to create comprehensive, seamless, and coordinated systems of care. The President's New Freedom Commission on Mental Health identified "unfair treatment limitations and financial requirements placed on mental health benefits in private health insurance" as one of several major obstacles to appropriate care for people with mental health disorders.[5] The IOM's report on improving the quality of health care for mental health and substance-use conditions[7] documents the lack of coordination for people needing mental health and substance-abuse treatment. This includes lack of coordinated general medical and behavioral health services within and between health care settings, and between health and other systems of care, such as vocational rehabilitation, social services, disability services, employee assistance programs, and criminal justice settings. This report identifies fragmentation in policy and financing and unclear accountability as important factors driving these discontinuities. In particular, financing arrangements such as carve-outs and managed behavioral health care may negatively affect the system's ability to create integrated, comprehensive systems of care. The IOM report makes four recommendations to improve individual outcomes through financing: (1) establish parity for coverage of mental health and substance-abuse treatment, (2) reorient the state procurement process to give the greatest weight to quality of care, (3) use quality-of-care measures in the procurement and accountability process, and (4) reduce emphasis on grant-based financing and increase use of funding mechanisms that link funds to quality-of-care measures.[31] Although the mental health parity acts have addressed the first of these recommendations and the ACA contains provisions for addressing the latter, much remains to be done to implement such practices, and research is needed to understand the linkages between these strategies and patient-centered outcomes.

Funding Streams in Silos and Barriers to Integration An important consideration in serving people with serious mental illnesses is how to provide a comprehensive array of services, many of which fall outside the traditional medical model, in a system where financing is "siloed" (ie, financed for discrete and limited sets of services), decentralized, fragmented, and largely uncoordinated. Funding for mental health services comes from a variety of sources, each with its own rules and regulations. Medicaid is the primary source of federal and state funds for mental health services, and it is a primary source of insurance for consumers with serious mental illnesses. The situation is more complicated for users with co-occurring substance-abuse disorders. Because of the differing eligibility requirements and benefits of the various funding streams, it is extremely challenging to commingle or blend funds targeting mental health and substance abuse.[286]

One particularly vexing question is how best to finance and provide care for co-occurring mental health and substance-abuse services. Almost 26% of people with serious mental illnesses also experience substance abuse or dependence.[185] Data from the 2010 National Survey on Drug Use and Health found that among the 2.9 million adults (aged 18 and older) with co-occurring mental illnesses and substance abuse disorder, 36% received no treatment for either condition. This rate was even higher for people with both co-occurring disorders in the justice system.[185] In addition, significant numbers of homeless individuals with co-occurring disorders who are eligible for either Social Security Income or Social Security Disability Income did not apply or were denied support because of missed appointments, lack of documentation, or inability to be reached by the agency.[289] Clark et al[216] reported that within five state Medicaid programs, people with serious mental illnesses and co-occurring substance-abuse disorders were more likely to use expensive emergency and hospital services and less likely to use community-based treatment compared with people with serious mental illnesses without substance-abuse disorders. In general, people with co-occurring mental health and substance abuse are at higher risk for a wide array of poorer outcomes, including high service use, repeated hospitalizations, higher costs of care, nonadherence to prescribed medications and treatment, homelessness, HIV infection, incarceration, and higher family burden.[293]

Mental health and substance-abuse services are financed through separate resource streams, delivered by different providers, and subject to different eligibility rules and limitations. Medicaid is the primary payer for mental health services, and states have expanded coverage to maximize federal matching dollars. Medicaid pays for about 15% of substance-abuse services (an optional service), and while most states offer some coverage for substance-abuse treatment, the benefits are not as extensive as for mental health. Additionally, people who receive disability income based on a substance-abuse diagnosis are not eligible for Medicaid, creating difficulties for blending funding and coordinating care.[286] Osher and Drake[293] provided a concise history of how the funding and organization of mental health and substance-abuse programs at the federal level kept eligibility and treatment separate, and how changes have evolved over time. In particular, they pointed out the powerful disincentives for service integration due to the fact that licensure monitoring and program administration are handled by different authorities. These divisions are exacerbated by medical education, licensure and credentialing requirements, quality assurance standards, differences in conceptual frameworks and philosophies of treatment, and mistrust and competition for limited resources.[286]

Sterling et al[294] noted that carve-out programs in both the public and private sectors delink mental health and substance-abuse services from other health care, reducing both access and quality of care. Private sector coverage for behavioral health often excludes substance-abuse treatment, even when other psychiatric services are covered. In the public sector, block grant funding may cover only community-based outpatient treatment and residential care, rather than the full spectrum of needed services. Additionally, Medicaid reimbursement often excludes psychologists, social workers, and family therapists, who are among the primary providers of substance-abuse treatment.[294] This has been addressed, in part, through the Medicaid Services Rehabilitation Option, which offers states a more flexible mechanism to provide mental health services, including (1) the ability to offer services in community settings or the client's home or work environment; (2) reimbursement for a wider range of professionals, including paraprofessionals; and (3) a broader set of services, such as life skills for everyday functioning.[295] Other barriers include annual dollar or service limits on substance-abuse treatment; restricting access to specific populations (such as pregnant women or homeless individuals); differences in organizational and professional cultures between general health, mental health, and substance-abuse providers; weak clinical linkages between primary care and behavioral health settings; policies around confidentiality that reduce or inhibit communication and coordination of care between settings and providers; and administrative resistance to blending funding because of problems of accountability in bundled payments.[294,296]

Despite these issues, a number of states and programs have successfully colocated services, blended funding streams (making it difficult or impossible to determine which source pays for which service), or "braided" funding streams (where multiple funding streams are used to provide a package of services but sources for services can be identified). There are many difficulties in improving access to co-occurring mental health and substance-abuse services, however. Two suggested mechanisms include pay-for-performance (P4P) and payment mechanisms to promote brief screening, brief intervention, and referral to treatment (SBIRT) for substance misuse. Use of P4P is just beginning in the behavioral health arena, in part because of concerns over adverse selection, but early results are not encouraging. (See the discussion of P4P in the section Patient-Centered Quality Improvement in Mental Health System and Provider Performance Measures, and Methods of Feedback). The American Medical Association Common Procedural Terminology and the Medicaid and Medicare Common Procedure Coding System provide reimbursement codes for screening, brief intervention, and referral, but once individuals are referred for treatment, the financing problems delineated above become apparent. In addition, states and private insurance companies must agree to adopt these codes to increase treatment referrals, and SBIRT codes have not yet been widely used in state Medicaid programs. In short, significant challenges remain if we are to integrate funding and distribution of care to adequately and appropriately provide services to people with co-occurring mental health and substance-dependence/substance-abuse disorders.

Medical Homes The primary care medical or health home model, discussed in detail later in this report, was developed to address needs for comprehensive, integrated, and coordinated services for children with special health care needs. It has been adapted to other populations with multiple and/or chronic conditions that require a wide scope of medical, behavioral, and social service interventions. Several public and private sector models have been recommended as potential solutions for improving outcomes for people with serious mental illnesses. These include (1) the integrated model with colocation of the full spectrum of medical and social services, as seen in the Cherokee Behavioral Health System in Tennessee (a federally qualified health center[FQHC]) and the Crider Center in Missouri (also a FQHC); (2) partnerships between community mental health centers and FQHCs such as the Integrated Policy Initiative in California; (3) the "Diamond Initiative" in Minnesota, an innovative payment model that uses a case-rate payment system[297]; (4) the Kaiser Permanente model of care, which fully integrates financing and service delivery; and (5) the Veteran's Health Administration model of care.[298] A newer form of the medical home, the behavioral health home, focuses on integration and coordination of care, including medical care, but is located within specialty behavioral health care settings. This model is discussed in more detail below, in the section National Health Care Reform and the and the Affordable Care Act.

Financing structures to promote the medical home model include monthly care coordination payments to support the medical home structure; a visit-based, fee-for-service component; and performance-based incentives to promote quality and efficiency goals. Many state Medicaid demonstration projects use one or more of these components. Fields et al[215] compared seven integrated systems of care and concluded that a modest per-member-per-month payment is a necessary incentive to motivate physicians to adopt care coordination mechanisms that are needed in a medical home model. They also suggested that performance incentives would be helpful for promoting coordinated and high-quality care.[215] While these elements are echoed by others, there is little consensus on the best way to incentivize comprehensive, coordinated care in the primary care system across the spectrum of needs for people with serious mental illnesses.[214] Common incentive mechanisms are reviewed below.

Evidence of the impact of medical home models on individual outcomes is limited but generally positive, including increased use of preventive care, improvements in physical health, and increased likelihood of having a usual source of care.[297] Shortell and McCurdy[298] suggested that payment mechanisms that increase greater interdependency between hospitals and physicians are necessary to encourage development of integrated systems.[298] Within the research and policy communities, however, there are questions about the efficacy and effectiveness of the medical home model applied to people with serious mental illnesses. Alakeson et al[297] have noted that primary care in the private sector is typically ill suited to meet the needs of people with serious mental illnesses because of restricted time and reimbursement for visits, provider training issues, the inability to directly address the wide service needs of this population, fee-for-service billing structures, and prohibitions in Medicaid for same-day billing for primary care and behavioral health care.[210,297]

Integrating Emergency Services With the Mental Health System of Care Psychiatric emergency department visits have increased significantly since the 1990s.[299,300] A recent study on the care process for psychiatric emergency department visits by Weiss et al[301] found that psychiatric service users experience longer wait times and longer lengths of stay. The authors speculated that this is due in part to lack of availability of inpatient psychiatric beds, resulting at least in part from low reimbursement rates for inpatient mental health hospitalizations. Similarly, the study showed that lengths of stay were significantly longer for people aged 41–59 when being placed for community-based services, and significantly longer for older people when placement required hospitalization. This suggests a serious gap in the availability of appropriate severity- and age-appropriate placements. The study showed how a lack of output-related capacity can have deleterious effects and highlighted the importance of linking and integrating emergency department services into the larger mental health system to improve access to aftercare options. The authors call for further research on length of stay at emergency departments that have various levels of integration with outside psychiatric facilities.[301] An earlier study of the general population in Canada found similar results.[302]

Innovative Financing at the State Level to Integrate Services Rules and regulations that are attached to the various funding streams often conflict with the goal of creating a comprehensive and seamless system of care for people with serious mental illnesses. Nevertheless, a number of states are funding clinically integrated mental health services, using strategies that include (1) flexible block-grant funds and state dollars to bridge services for people with co-occurring disorders; (2) modification of regulations regarding specific service definitions and billing codes; and (3) use of risk contracts and administrative services–only mechanisms through managed care organizations that manage a diverse portfolio of funding streams and so are able to create the impression of a coordinated system from both provider and client perspectives.[286]

California, for example, adopted a recovery-oriented approach using a “full service partnership”—a flexible-funded collaboration between mental health agencies, law enforcement, education, social services, and housing and employment agencies. The program, which provides seamless access to individualized recovery-oriented services for people with serious mental illnesses, has resulted in lower rates of homelessness, incarceration, hospitalization, and unemployment.[303] California also tested the financial viability of an ACT model that used an integrated service agency model to provide a comprehensive array of behavioral, medical, social, housing, and employment services. Over a 4-year period, costs associated with ACT were lower for the treatment group than for a randomly assigned control group.[304] The program also demonstrated increased workforce participation in both urban and rural areas, reduced hospitalizations, increased program retention, and increased leisure and social activities.[304] No significant differences were noted for long-term hospitalizations, arrest, conviction, measures of self-esteem, symptomatology, substance abuse, homelessness, or QOL. The capitated integrated model was helpful for creating a unified service delivery structure and for creating some positive individual-level outcomes.[304,305] An older study of an attempt by the Oregon Health Plan (the state Medicaid program) to integrate mental health and substance-abuse treatment showed that it evolved into a carve-out approach. Issues that impeded integration included changes in the administration and management of substance-abuse benefits, financial losses experienced by the health plans, lack of provider training, and lack of incentives for providers to refer clients to substance-abuse treatment.[306]

There are also examples of recent innovative state strategies to improve care for populations with serious mental illnesses, but outcome data are not yet available. For example, Maryland recently created a series of innovative financing strategies[307] including the Creative Alternatives program—a team-based comprehensive case management program for high-risk psychiatric patients that offers a per-member-per-month fee of $2 410 to provide all mental health and psychiatric services. The program pays for the member’s regular psychiatric treatment, therapy, medications, and case management, as well as any supportive care needed. In addition to usual care, the program also pays for all psychiatric-related emergency department visits and hospitalizations. There are several other programs in Maryland that, while not explicitly targeted to people with serious mental illnesses, are likely to include this population. These include Connecting Patients with Medical Homes and the Shore Wellness Program, both of which target high-risk or high-utilization patients at risk for rehospitalization and use a lump-sum capitated payment system to the health system. The Maryland Multi-Payer Patient-Centered Medical Home also targets payers providing coverage to government and private sector employees using a shared-savings approach.[308]

Missouri also recently initiated a 3-year statewide pilot program to integrate primary care provided by FQHCs and behavioral health services provided by community mental health centers. Initial reports suggested that critical elements of successful implementation included strong leadership; readiness for interagency collaboration; knowledge of the complexities of each agency’s organizational structure, culture, funding mechanisms, and client base; history of collaboration; local political conditions; and sufficient seed funding.[309]

In addition to these innovative state programs, the CMS Innovation Center recently announced its first round of innovation awards. The Medicaid Emergency Psychiatric Demonstration will test whether Medicaid can support higher quality care at a lower total cost by reimbursing private psychiatric hospitals for certain psychiatric services. Historically, Medicaid has not paid psychiatric hospitals for these services without an admission to an acute care hospital first. This demonstration project provides $75 million over 3 years to 13 states.[310] Under the Bundled Payments initiative, CMS will link payments for multiple services received during an episode of care, and providers will have the flexibility to determine which services should be bundled together. CMS is currently seeking proposals to test four different models of bundled payments.[308] Other CMS Innovation initiatives not explicitly targeting mental health, but which may affect individuals with mental illnesses nevertheless, include the Community-Based Care Transitions Program, Independence at Home, the Pioneer Accountable Care Organization Model, and the Comprehensive Primary Care Initiative.[310] These new models of care offer significant opportunities to test how different financing arrangements can improve outcomes for people with serious mental illnesses.

Frank Melville Supportive Housing Investment Act of 2010 The Frank Melville Supportive Housing Investment Act of 2010 made $85 million in funds available to state housing agencies to provide affordable housing for people with disabilities. US Department of Housing and Urban Development Section 811 provides affordable housing linked with community-based supportive services for the country's most vulnerable disabled populations. For the first time in the history of the Section 811 housing program, integrated programs for people with serious mental illnesses are offered through partnerships with state Medicaid agencies, thus providing an opportunity to more easily combine housing with mental health services.[201] The legislation states that housing offered under this law is to benefit low-income and very low–income people with disabilities; it provides no mention of any exclusion based on a record of having drug offenses, nor do the recent amendments mention eliminating this restriction.[311,312]

Summary and implications. Integrated systems of care are viewed as an important and viable mechanism for meeting the complex, chronic service needs of people with serious mental illnesses. Key questions about the best ways to fund integrated systems remain unanswered. Funding sources are diverse, complex, and laden with rules and regulations that create barriers to integration. There are a variety of experiments to test different financing tools to improve care for populations with serious mental health disorders. Opportunities for CER and PCOR are ripe and need to be pursued. In particular, more research is needed that links financing vehicles and arrangements directly to patient-centered outcomes.

National Health Care Reform and the Affordable Care Act. The ACA,[313] enacted in March 2010, significantly increases coverage and financial assistance to low- and moderate-income people and makes sweeping changes to public insurance programs through benefit expansions and opportunities for demonstrations to address costs, promote efficiency, and improve coordination for dually eligible consumers of services. The law also provides new standards for private health insurance, places limits on cost sharing and premium requirements, and establishes new rules to ensure access to coverage. The ACA further authorizes significant funding to states, local governments, employers, community organizations, and other entities through existing and new grants and programs to implement the many provisions in the law.[314] Current federal funding levels for the ACA are estimated to be $12.2 billion, with $4 billion going to states and $8.2 billion allocated to the private sector.[315]

The ACA offers significant opportunities to test new payment and organizational models to better serve people with mental illnesses and improve their outcomes. In particular, the ACA creates opportunities for states to develop a behavioral health home model of care to address the needs of people with chronic medical and behavioral health conditions. The intent of the legislation was to help states promote patient-centered care by improving the experience of care and the health of populations, and reducing the per-capita costs of health care. The Health Home model is designed to specifically address the service needs of people with serious mental illnesses and provide enhanced integration and coordination of primary care, behavioral health care, and long-term community services for people with chronic illnesses. The legislation is also designed to address the shortcomings of serving people with serious mental health and substance-related needs in primary care medical homes. States wishing to take advantage of this option will receive a 90% federal match for eight quarters.[316] States have a number of options for how to organize and finance services within this arrangement, including an in-house model, in which all required services are housed within a single organization; a colocation model, where different organizations operate as a team to provide services; and a facilitated referral model, where services are offered in more than one location. The legislation also allows states to adopt a tiered payment structure to account for severity of condition and the capabilities of designated providers or health teams. States are not limited to the "per-member-per-month" payment mechanism.[317] These changes raise an important research question: How do patient-centered outcomes associated with the behavioral health home model compare with those associated with the primary care medical home model?

Under health care reform, the role of Medicaid and other public insurance programs that fund most care for people with serious mental illnesses will likely expand.[318] Garfield et al[319] noted that under the ACA, states have the option to provide "benchmarked" coverage for new beneficiaries, which will likely be less than the full level of Medicaid benefits. Thus, new beneficiaries are likely to experience gaps in coverage for mental health–related needs. Medicaid expansions and "essential benefits packages" are two key policy options for states.[319] Based on an analysis of data from the National Health Interview Survey, Long and Stockley[320] suggested that comprehensive reforms are more successful at addressing gaps in coverage than limited, narrower efforts. Through a roundtable forum with national and state policy makers, the Kaiser Commission on the Uninsured highlighted the differences in coverage needs between people with mild/moderate mental illness and those with serious mental illnesses, as well as the lack of consensus regarding future coverage decisions by states. Policy makers did agree that the medical home model is the most appropriate mechanism for meeting the needs of people with serious mental illnesses and that the current public health system lacks adequate capacity and coordination to meet the needs of such beneficiaries who are newly eligible.[321]

In addition to these reforms, new state insurance exchanges and Accountable Care Organizations are in the early stages of formation and program development, offering researchers and policy makers a unique opportunity to study and influence program development. There are many outstanding questions regarding what the Accountable Care Organizations will comprise, what their goals are, and how they will function. Additional key questions around insurance exchanges and integrated systems include the following: What is the best way to integrate services for people with serious mental illnesses and improve patient-centered outcomes? What are the best financing tools and policies to ensure appropriate, timely, comprehensive, and high-quality care for people with serious mental illnesses? How will the new financing structures affect patient-centered outcomes?

Implications for CER and PCOR The research on resource acquisition and distribution is largely focused on questions of policy and service delivery, not on patient-centered outcomes. While the extant literature may not have been intended to address these outcomes, it is now clear that studying the links between financing approaches and individual outcomes is critically important. The lack of any systematic reviews, or even individual studies on key topic areas, makes this a fertile area for investigation of the links between patient-centered outcomes and the myriad topics covered in this review: costs, capitation and managed care, carve-outs, prescription drugs, and integrated systems of care. Additionally, an important but seemingly neglected area of study is the impact of funding on quality of care. The ways that funding streams are used or integrated have significant potential to limit or place ceilings on the types and scope of services and benefit packages, which in turn can affect quality of care and individual outcomes. Health care reform offers important opportunities to better understand these issues as they relate to people with serious mental illnesses. Because implementation is so recent, we do not yet know the outcomes of these experiments.

Measures and metrics for costs and expenditures tend not to be linked to patient-centered outcomes in any meaningful way. Instead, they are limited to macro- or system-level variables, focusing on total or average expenditures for care in various settings, among different providers and for specified services. This was to be expected to some degree, as most articles we reviewed do not focus on the individual consumer, and they present limited patient-centered outcome data at the systems level. This gap raises fundamental questions about how to collect data related to patient-centered outcomes and embed them in the claims and administrative databases on which most cost and expenditure analyses are based. Indeed, methods for integrating such data warrant further exploration in and of themselves.

Another consistent theme in our review was the need for more subpopulation analyses and analyses at more discrete levels of measurement. Individuals with serious mental illnesses belong to a variety of subgroups that might be classified using any number of conceptual schemes, including age, gender, race, diagnosis, underserved status (economic, insurance, geographic, access to care), homelessness, veteran status, physical or addiction comorbidities, or involvement with the justice system. Research clearly shows differences among these groups, and combining these subpopulations may mask significant variability in the effects of different financing tools on outcomes. New CER and PCOR projects evaluating financing mechanisms should address outcomes for these subpopulations.

Similarly, more discrete and disaggregated analyses would be useful for understanding the effects of specific aspects of capitation, managed care, carve-outs, and other financing structures on a number of measures. These include (1) mental health status, functionality, and patient-centered outcomes for specific subpopulations, including elderly individuals, those in underserved and rural areas, and people grouped by diagnosis or gender; (2) shifts in costs from private to public sectors, and from plans and employers to individuals and families; (3) how risk assessment and assignment are determined and how this affects patient-centered outcomes; and (4) what incentives embedded in carve-out plans and management will ensure provision of quality care.

This review also identified a number of gaps in the literature and specific research needs related to resource acquisition and distribution of funds for services to individuals with mental illnesses. The field would benefit from two activities in particular, both with a focus on patient-centered outcomes: a systematic review of state efforts to blend funding streams and development of better methods for comparing resource allocation and distribution across geopolitical and service jurisdictions (state-level comparisons).

External Influences and Unintended Outcomes Economic and political forces affect how policy and financing structures are developed and implemented, how health systems are developed, how providers are reimbursed, and how consumers access services. Financing structures and source of coverage have been linked to varied disparities in access, quality of care, and outcomes. Moreover, the economy exerts great pressure to contain costs, particularly as the costs of state Medicaid programs continue to soar. The expansion of coverage under health reform intensifies this pressure. All the elements that shape health care reform—the economy, national and state elections, lobbying efforts—will shape financing policy, resource acquisition, allocation, and distribution for mental health services. Additionally, the ways in which financing interfaces with service delivery are significantly shaped by how public and private care systems interpret and implement policy. This can best be seen in the wide variation across state Medicaid programs. Large managed-care organizations in both sectors have a leadership role to play in establishing viable systems of care for people with serious mental health problems.

In addition, small changes in policy can produce unexpectedly large effects in care provision. For example, adding a billing code for care coordination could create strong incentives for systems to provide such services. It is equally important to understand how different agents of change are affected. For example, a plan to decentralize financing from a state agency to local entities may save money for the state, but county mental health departments and local service providers may experience major disruptions in contracting, resulting in disrupted care for service users. Thus, the benefits and costs of policy changes may not be held equally throughout the health system. Clearly, more research on comparative effectiveness and patient-centered outcomes is needed to fully understand how financing policy affects individual service users.

Key Leverage Points Because services for people with serious mental illnesses are financed largely through the public sector, the most influential leverage points with respect to resource acquisition and distribution include federal policies for Medicaid, Medicare, block grants, and other funding sources. States have the flexibility to alter their Medicaid financing mechanisms, including by changing the ways that capitated plans are designed and implemented, designing risk and risk-sharing arrangements between plans and providers, calculating case mix–based reimbursement and enhancements, implementing changes in billing codes and reimbursement methods, and adding new payment mechanisms to support integrated care models such as medical or behavioral health homes and peer-provided services. Moreover, there are significant opportunities to study the development and implementation of the new Accountable Care Organizations and state insurance exchanges under current health reform, as well as the roles played by state insurance commissioners in shaping policies that affect people with serious mental illnesses.

Another major leverage point would be to develop methods to systematically embed common patient-centered outcome variables in administrative and claims data. This would take resources, long-term commitment, and policies requiring or incentivizing reporting on the part of states and providers. While this task may seem daunting, we stand to gain a great deal of insight from databases that link expenditures, use, and costs to patient-centered outcomes. This knowledge could inform changes to financing structures that create platforms for service delivery, with the goal of improving outcomes for people with serious mental illnesses.

Finally, the private insurance market presents an important leverage point. While parity laws have been helpful in increasing access, the extent of their impact is not clear. Parity laws notwithstanding, it may be that incentivizing the private sector to promote better preventive and early intervention services, medication adherence, and continuity of care may reduce transitions of individuals with serious mental illnesses to publicly funded systems of care. Large employers and HMOs have the ability to scale their services to meet the mental and behavioral health needs of people with serious mental illnesses.

Summary and Implications A review of the literature on financing for people with serious mental illnesses reveals a number of important limitations and opportunities for CER and PCOR. Specifically, studies on cost trends do not address patient-centered outcomes but are useful for understanding the broader perspective on how services are financed. Parity is useful for some purposes, but because most people with serious mental illnesses receive publicly funded services, this vehicle affects a smaller proportion of individuals with these disorders. Increased coverage and lower out-of-pocket costs for consumers may be useful for reducing the rate of disability of disability through earlier intervention and more effective treatment of acute episodes.

Capitation, carve-outs, and managed care have been increasingly used to fund and manage behavioral services for individuals with serious mental illnesses. Overall, carve-outs for mental and behavioral health services have resulted in cost savings and reductions in inpatient hospital use and a shift in utilization from inpatient to outpatient settings across sectors and over time. The literature clearly shows that carve-outs can create powerful and disparate incentives and disincentives, depending on how risk and other elements are handled in contracts. The variation in the experience of different states highlights the importance of understanding the details of contractual arrangements within the context of local political and health systems.

Consumer-directed care is an important component of patient-centered care and can promote engagement and satisfaction among service users. Financing mechanisms developed to achieve consumer-directed care appear to be viable for people with serious mental illnesses. Finally, integrated systems of care, including primary care medical homes and behavioral health homes, are viewed as important and viable mechanisms for meeting the complex, chronic service needs of people with serious mental illnesses. Key questions remain, however, about the best ways to fund integrated systems. Funding sources are diverse, complex, and laden with rules and regulations that create barriers to integration. A variety of experiments are underway to test different financing tools to improve care for populations with serious mental illnesses.

Financing structures for services for people with serious mental illnesses are strongly influenced by a number of factors, including macrolevel economic trends and political forces, policy interpretation and implementation, and state and local capacity. Research opportunities in comparative effectiveness and patient-centered outcomes are ripe and need to be pursued. In particular, many ACA initiatives provide important opportunities for naturalistic experiments testing different ways to address long-term difficulties in financing services.

Populations Served

The depth and sprawl of the mental health care and service delivery system are extensive, and its boundaries are indistinct. The array of individuals who interact with this system is correspondingly vast, with consumers of mental health services having a wide range of attributes, many of which have bearing on the types of care and services these individuals are attracted to and those that are appropriate and effective in meeting their needs. Moreover, this diverse population encompasses a variety of subgroups that might be categorized in a number of meaningful (albeit not always permanent) ways. These include gender, culture, life course, diagnosis, illness course or severity, personal history, socioeconomic status, addiction or physical comorbidities, housing status, involvement with the justice system, and level of engagement or reluctance to be involved with the service system. Our narrative review showed that many of these variables are powerful moderators and mediators of treatment effects and, most likely, patient-centered outcomes. However, our understanding of how best to tailor and match care and services to the particular characteristics and preferences of individuals is underdeveloped. CER and PCOR promise methods of moving toward a much better understanding of how to best serve the diverse individuals in this population.

Care and Service Delivery for Individuals Diagnosed With Serious Mental Illnesses: Structures, Service Packages, Delivery Methods, and Delivery Characteristics

Throughout the United States, there is now a great deal of focus on reform of health care funding and delivery systems, driven largely by fiscal crises and by the frustrations of citizens and businesses about inadequate access, increasing expenses, poor coordination of care, and inadequate and disparate outcomes. Combined with, and arguably propelling, these reform efforts is a contemporary philosophy that emphasizes service users' preferences for health-related outcomes rather than more conventional, paternalistic approaches to care provision. Such factors have resulted in both the ACA and numerous state initiatives to redesign how care is delivered. Taken together, these reform efforts present unprecedented opportunities for evaluating redesigned care delivery structures and implementing services guided by the preferences of those who receive care.

There is a well-established, long-standing, and continuing need to improve care quality for individuals with serious mental illnesses.[5,7,322] In this section, we review the philosophies and models of care that guide and influence mental health care and service delivery, the key characteristics of an effective delivery system for those with serious mental illnesses, and the interventions and programs that, based on current evidence, should be considered as components of the package of services available to this population.

When we set out to map the care and service delivery system in preparation for our literature review, we anticipated finding aspirational philosophies of care (eg, psychosocial rehabilitation movement, recovery movement) dictating essential characteristics of care delivery (eg, effective engagement, continuity of care). We expected to identify models of care with well-articulated and well-delineated domains (eg, the CCM) that would define an associated package of services (eg, case management, crisis services, education, self-management support) that would be reflected in particular care delivery structures (eg, the Patient-Centered Medical Home, the Clubhouse Model). But in an ironic reflection of what it must be like to organize and provide services in this complex system, we struggled to appropriately classify these models, services, and methods. As has been pointed out by many who have conducted reviews, terms are inadequately defined (eg, continuity of care), are used inconsistently (eg, ACT used both as a model of care and as a package of services), and often have significant commonalities and overlapping components (eg, the CCM and integrated care).

One of the key challenges to conducting CER as it relates to care delivery for those with serious mental illnesses will be to agree upon a common taxonomy, clear definitions, and consistent use of terms. Until that agreement is in place, classification of the components of a model of care and service delivery is somewhat arbitrary. As a consequence, we have organized our review according to where we think these components best fit in the model we developed, but we acknowledge that they may fit in multiple categories.

Care and Service Delivery Models and Structures

Psychosocial Rehabilitation. As the locus of care shifted from the psychiatric inpatient hospital to the community during the deinstitutionalization movement of the 1960s and 1970s, an unintended consequence was that the mental health system became more fractured, and care and services became less accessible and less coordinated. This left many individuals unable to get their needs met or to navigate the overwhelmingly complex new system. Simultaneously, the care culture was beginning to migrate from an illness model focused on presumed limitations to one focused on social functioning. In the wake of these changes arose the psychosocial rehabilitation (PSR) movement. The goal of PSR is to help individuals develop the skills needed to participate in the community and lead a fulfilling and meaningful life with the least amount of professional support. Interventions can be classified as PSR to the extent that they are directed toward functional improvement and social inclusion,[323] meaning that PSR is not a technique but rather a philosophy. PSR needs are determined by the individual engaged in services, depend on his or her environment, and extend beyond clinical outcomes to include functional and interpersonal outcomes. Employment, leisure pursuits, social functioning, QOL, and reduced family/carer burden are examples of patient-centered outcomes that may be met by evidence-based PSR interventions. Such interventions include vocational rehabilitation through SEm or relationship building through family interventions, peer support, and social skills training.[324] PSR philosophies of autonomy and self-determination align well with patient-centered philosophies of care delivery.

Recovery Model In the late 1980s, first-person accounts documenting the experience of recovery from serious mental illnesses began to appear.[325,326] By the 1990s, reports of long-term follow-up studies[327–331] began to challenge the pessimistic view of outcomes that was dominant at the time. The recovery model was taking root,[332] producing a new optimism for consumers and providers of mental health services, and it has since influenced service delivery around the world.[333] This model emphasizes that the service user should hold primary control over the recovery process, and that the process should account for the autonomous rights and phenomenological experiences of that person.[334] The concept of recovery, however, remains ill defined, and most definitions have been developed by consensus rather than empirically. The recovery model has also been used in multiple ways (as a model of care, a process, and an outcome) and has been criticized for its lack of a strong empirical base, although calls to establish a scientific agenda have been made.[335,336] As an outcome in the literature, *recovery* has been defined both in the short and long term as remission of symptoms, resumption of a prior level of functioning, or achieving a meaningful life.[337] Correlates associated with recovery as an outcome have been described,[338] and limited research has examined recovery as a process.[52,339]

A distinction has been made between clinical recovery—the traditional model—and personal recovery. The former is outcome based, is rated by an observer, and emphasizes symptom reduction and improved functioning through effective mental health service intervention. In contrast, personal recovery is now understood as a highly unique process,[340] defined by individuals, that may require neither symptom reduction nor mental health service utilization.[341] Like PSR, the recovery model is not a specific set of techniques, but rather a philosophy with a collection of recovery-oriented, evidence-based interventions that include shared decision making, supported cognition, supported services, and peer support.[336] Also like PSR, the recovery model aligns nicely with patient-centered care. Individual preferences, consumer-directed care, and person-centered outcomes are seen as key components of both approaches. Customization of care and services to address the unique needs of the individual, with the goal of achieving self-defined recovery outcomes, is central to the recovery philosophy. Ripe for future CER and PCOR are empirical investigation of guidelines for recovery-oriented practice,[342] links between different recovery-focused approaches and patient-centered outcomes, and comparisons of differential effectiveness of recovery-oriented mental health services at levels of the individual, provider, organization, delivery system, and society.[341,343]

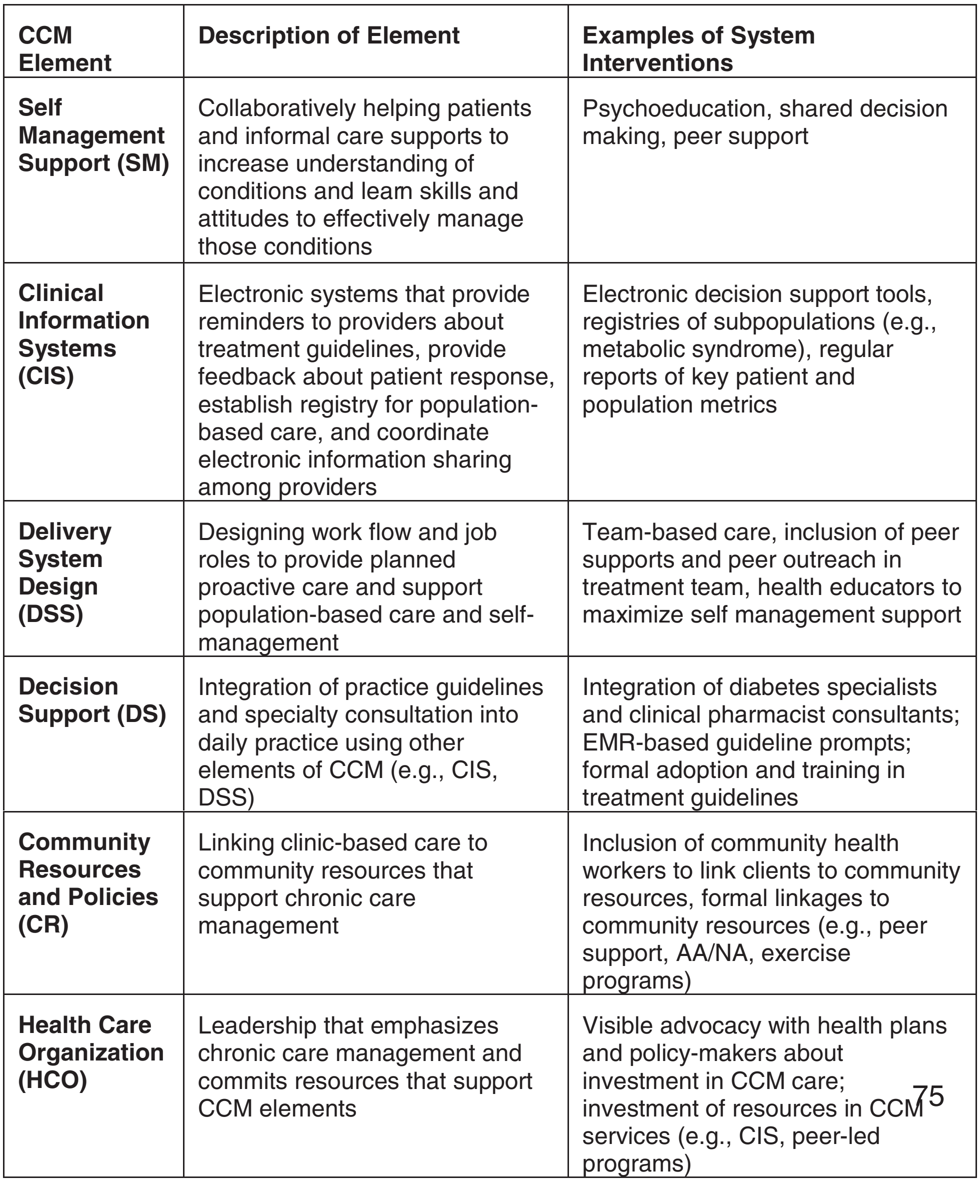
Chronic Care Models People with serious mental illnesses are at increased risk of premature mortality, primarily due to preventable chronic conditions including heart disease, diabetes, cancer, stroke, and pulmonary disease,[21–23] some of which are caused or worsened by metabolic side effects of psychoactive medications.[344–349] In addition to being at increased risk for life-threatening chronic conditions, individuals with mental illnesses may be less likely than those without such disorders to receive guideline-concordant preventive care.[350,351]

The last 20 years have seen an increasing effort to develop health care delivery models that emphasize a comprehensive approach to effective care and management of chronic disease. These models focus extensively on developing care delivery and financing systems that increase continuity of care with a care team that integrates medical and behavioral health, coordinates efforts across different care providers and institutions, provides increased knowledge about clinical guidelines and the comparative effectiveness of various treatment options, and increases support and education to service users to help them engage in self-management. These efforts have resulted in a number of overlapping care delivery models that incorporate common elements, and they have driven research agendas to assess their overall effectiveness and the relative impact of their respective components. These models include the CCM,[352] collaborative care,[353] integrated care,[354] and the Patient-Centered Medical Home.[355] Although they are not synonymous with each other, they are at times used interchangeably. We have chosen to review them together, as the underlying elements share a common heritage and values.

Historically, these collaborative care models have focused on primary care delivery and have only recently been applied to care for individuals with serious mental illnesses, primarily bipolar disorder,[356–358] although key components of the models (eg, care management) have been used extensively in mental health treatment for decades. The advent of health care reform, however, appears likely to significantly expand the focus on chronic disease management and the integration of mental health treatment with primary care using vehicles such as Accountable Care Organizations.[359]

The representative CCM is best considered a "foundation of management"[360] rather than a specifically defined treatment, and it incorporates six core elements (reviewed in figure 8, adapted from Woltmann et al[361] and Bodenheimer et al[362]) along with a set of specific services commonly used in clinical trials as representative of each element. Across different trials, the model's six elements are each defined by a range of services, tasks, and interventions, and most trials include interventions of only two to four elements, rather than all six. Some services, however, are commonly used in almost all studies of collaborative care (eg, care management).

Components of the CCM have been shown to be effective in improving patient outcomes in diabetes, congestive heart failure, asthma, depression,[362,363] and chronic obstructive pulmonary disease,[364] although few studies have included all or even most of the six components.[361] In a meta-analysis of 112 studies in which one or more CCM elements were tested, Tsai et al[363] found that overall, pooled across diseases and CCM elements, CCM interventions were effective in improving primarily process



CCM Element	Description of Element	Examples of System Interventions
Self Management Support (SM)	Collaboratively helping patients and informal care supports to increase understanding of conditions and leam skills and attitudes to effectively manage those conditions	Psychoeducation, shared decision making, peer support
Clinical Information Systems (CIS)	Electronic systems that provide reminders to providers about treatment guidelines, provide feedback about patient response, establish registry for population-based care, and coordinate electronic information sharing among providers	Electronic decision support tools, registries of subpopulations (e.g., metabolic syndrome), regular reports of key patient and population metrics
Delivery System Design (DSS)	Designing work flow and job roles to provide planned proactive care and support population-based care and self-management	Team-based care, inclusion of peer supports and peer outreach in treatment team, health educators to maximize self management support
Decision Support (DS)	Integration of practice guidelines and specialty consultation into daily practice using other elements of CCM (e.g., CIS, DSS)	Integration of diabetes specialists and clinical pharmacist consultants; EMR-based guideline prompts; formal adoption and training in treatment guidelines
Community Resources and Policies (CR)	Linking clinic-based care to community resources that support chronic care management	Inclusion of community health workers to link clients to community resources, formal linkages to community resources (e.g., peer support, AA/NA, exercise programs)
Health Care Organization (HCO)	Leadership that emphasizes chronic care management and commits resources that support CCM elements	Visible advocacy with health plans and policy-makers about investment in CCM care; investment of resources in CCM services (e.g., CIS, peer-led programs)

Fig. 8. Collaborative Chronic Care Model elements and examples.

and intermediate clinical outcome measures (eg, HbA1c control) for chronic diseases commonly seen in primary care. Using metaregression, they examined the independent effects of delivery system elements (delivery system design, self-management support, decision support, clinical information systems) and found that delivery system design and self-management support improved clinical outcomes and process-of-care measures. Decision support improved process measures, but clinical information systems did not produce benefit. None of the elements resulted in improved QOL. There is also evidence that combining CCM elements, especially when including self-management, produces synergistic effects, including fewer hospitalizations, shorter lengths of stay, and fewer emergency or unscheduled visits.[364–366] The evidence for cost-effectiveness is equivocal[366,367] and has considerable variation in how economic impact is defined (eg, incremental individual costs, health care utilization, lost productivity, cost utility). These recent reviews emphasize the importance of significantly expanding research to understand the benefits and costs to practices, payers, and service users, and to determine the number and specificity of components essential to producing economic benefit.

The CCM has an extensive history of being used in efforts to improve the primary care treatment of depression in a variety of delivery systems, including integrated health systems, the Veteran's Health Administration (VA), managed care organizations, preferred provider organizations, and community-based organizations (eg, FQHCs). Two recent systematic reviews and meta-analyses of collaborative care treatment for depression found benefits. Bower et al[368] found that collaborative care increased antidepressant use and improved depression symptoms most effectively when case managers were mental health professionals and received regular supervision. Thota et al[369] conducted a meta-analysis and systematic review of 32 high-quality collaborative care depression studies published between 2004 and 2009 and demonstrated "robust evidence" of effectiveness of collaborative care in improving depression symptoms, adherence to treatment, response to treatment, remission of symptoms, recovery, and satisfaction with care, as well as slightly improved QOL/functional status. They found that amount of case management, intervention length, and quality of execution of the intervention did not relate to depression symptom improvement. However, three modifier variables did relate to the size of the effect: the type of organization (community-based organization—largest effect; VA—least), type of case manager (RN—largest, masters-level counselor—least), and number of collaborative care components out of the eight components assessed (inclusion of four to five components had the largest effect; less than four or more than five had the least effects).

An earlier review by Gilbody et al[370] found that collaborative care (primarily defined by depression case management) produced beneficial outcomes, albeit at an increased cost. A later systematic review of the economics of collaborative care for depression,[371] published in conjunction with the review of Thota et al[369] cited above, found good economic value across different measures of economic benefit among studies. Of those measuring economic benefit in terms of averted health care or productivity loss (seven studies), 57% found benefit. Of those measuring both benefits and costs (five studies), 60% found lower cost due to reduced health care utilization or increased productivity, and of those that measured economic benefit based on cost utility (six studies), 83% found that care was cost-effective.

Although the use of the CCM for primary care depression treatment has been the subject of extensive research, its use as a framework for treatment of serious mental illnesses has been minimal. A notable exception to this is bipolar disorder, for which several RCTs have been implemented in a variety of health systems using CCM intervention elements.[356–358,372] Bauer et al[356,357] conducted an RCT of the CCM specifically for service users with bipolar disorder in 11 Veterans Health Administration Medical Centers. The intervention randomized hospitalized patients to either an outpatient "specialty team" mental health clinic or psychiatrist and registered nurse care coordinator or usual care managed by a psychiatrist. The intervention consisted of multiple components, including consumer self-management support, provider decision support, extensive nurse case management follow-up, and coordination with other providers, hospital liaison, and urgent access. The study found broad improvements in outcomes, including reduced length of manic episodes; improved social role function, mental QOL, and treatment satisfaction; and cost neutrality. Later, Kilbourne et al[373] reanalyzed data from this study and demonstrated that outcomes were comparable for those with and without co-occurring substance-use problems. Similarly, Simon et al[358] used a comparable CCM intervention in a study conducted in an integrated delivery system (a group model prepaid health plan), replicating some of the Veterans Health Administration findings, including reduced symptoms and length of manic episodes. He also found that the costs of the intervention group were modestly higher than for the usual care control group.

A recent meta-analysis and systematic review of 57 RCTs of CCM interventions[361] reported effects on mental health symptoms or mental QOL regardless of whether the condition of focus for the intervention was a mental health disorder. The meta-analysis found beneficial effects on physical and mental health outcomes (depression symptoms, mental QOL, physical QOL, and social role functioning) at little or no net increase in costs, supporting the findings from Bauer et al.[357]

Integrated Care Models An AHRQ Evidence Report published in 2008[372] reviewed the evidence for integrating mental health and primary care services. The report examined integration of behavioral health services within primary care settings, as well as the reverse. The former focused primarily on depression, anxiety, and substance-use disorders. The report's authors concluded that integrated care within primary care environments clearly had benefits over usual care, but neither the extent of integration nor the implementation of structured processes appeared to relate to improved outcomes. The Butler review[374] identified only three studies of primary care integration within specialty care outpatient settings, and all were conducted within integrated delivery systems (two VA and one HMO) with the inherent advantages of such systems in terms of coordination and flexibility of funding. These studies identified benefits from "reverse integration" (consisting primarily of an advanced practice nurse to conduct screening and referral or a nurse case manager to coordinate referral and follow-up). Benefits included reduced costs and improved QOL, physical well-being, and quality of medical care (eg, diagnosis of common medical problems, increased preventive care). Whether reverse integration can be effectively implemented within community settings where funding and care are not integrated has yet to be demonstrated, due to the many barriers in these settings, including cultural differences between systems, policy and payment barriers, and workforce training limitations.[297]

Unintended Consequences and External Influences The ACA established a "health home" option under Medicaid that serves enrollees with chronic conditions. This component of the ACA allows states to implement a behavioral health home for individuals with serious mental illnesses and/or substance-use disorders. The likely result is that behavioral health agencies will become the primary health home for people with serious mental illnesses, responsible for ensuring that all health care needs are met and coordinated. According to a recent report by the SAMHSA-Health Resources and Services Administration Center for Integrated Health Solutions,[317] this responsibility can be met with one of the three models discussed earlier: an "in-house model" in which the behavioral health agency provides all the primary care and behavioral health services needed by their service users; a colocated partnership model in which the behavioral health agency arranges a primary care agency to provide primary care services onsite; or a facilitated-referral model in which the behavioral health agency screens for physical health conditions and establishes processes to ensure that adequate and coordinated care is provided in the community using a medical case manager. This is a profound and innovative change with inadequate research evaluating the key elements and structures necessary to adequately meet the needs of service users. It has potential to significantly improve medical care for people with serious mental health disorders, but it also carries risk, as agencies that have little experience or knowledge of primary medical care assume that responsibility.

Characteristics and Methods of Care and Service Delivery. The core of any process designed to improve outcomes for those with serious mental illnesses should comprise evidence-based services, delivered by care systems and structures, that are adapted for different populations and responsive to the articulated preferences of those receiving services. It has become clear that interventions for addressing the complexities of those living with chronic illnesses—especially those with a serious mental illness—must be embedded in a coherent and interactive system of care that empowers and supports service users.[352] Of the variety of care models developed to address the complexity of delivering care to those with chronic conditions, some are specific to serious mental illness and others are focused more broadly on chronic medical disease. Both are influenced by a host of biopsychosocial variables that can negatively or positively affect a person's management of and adaptation to a given condition. Evidence exists for several characteristics of care delivery that are necessary, if not sufficient, to achieve improved patient-centered outcomes. These include engagement of service consumers, continuity of care with clinicians or teams, effective communication and a strong working or therapeutic relationship between consumers and providers, continuity of treatment across modalities (eg, inpatient to outpatient care), provision of information and education about illness and treatment, training and support in skills to manage the chronic condition, and supports within the system to maximize the likelihood that the right treatment is given at the right time to the right person according to their desires. We review these key components of care in the sections that follow.

Effective Engagement in Initial and Ongoing Treatment Planning Individuals enter the mental health system in myriad ways, including well beyond the onset of symptoms,[375–377] and often at critical periods, such as through a visit to the emergency department during an acute episode of illness or after an arrest. An individual's initial experiences with the system may significantly affect the course of their care, and yet the best approaches for engaging individuals in care at various entry points are poorly understood. Recent evidence suggests that these initial experiences can be unpleasant and, at worst, traumatic.[301,378]

When an individual comes into contact with the care delivery system, it is often unclear what first step is likely to result in the best outcomes for that person. For example, are initial resources better spent on engagement and developing care relationships, or on screening and coordinating triage to appropriate services? Accessing the system is only the first step in an ongoing process of planning, obtaining, and maintaining stable care and services. Empirically validated interventions are of little worth if we do not understand the variables that influence initial and prolonged engagement and disengagement from mental health services. Our knowledge of the extent to which individuals with serious mental illnesses fail to access the mental health care system is limited[379] and based on dated epidemiologic surveys.[182,184,380] What we do know suggests that a large proportion of those who might benefit from services fail to seek them.[379] Common reasons for not seeking care include not perceiving a need for treatment, believing the problem will self-correct, wanting to solve the problem on one's own, and the perception that treatment will not be effective.[184] This raises ethical and practical questions of how and whether to connect with marginalized populations that may not want to participate in care or services, or may not want what is typically offered. This also highlights the need to better understand how to develop services that are appealing, have value to consumers, and facilitate engagement, and subsequently how to effectively inform consumers about those services and how to access them.

Both engagement and disengagement appear to be poorly conceptualized in the literature, are rarely defined explicitly, and lack acceptable measures.[381] Consequently, attendance is commonly used as a proxy for engagement, despite acknowledgement that attendance alone is not sufficient for engagement and may, in fact, represent nothing more than fear of involuntary treatment. Other conflating variables that are often used to estimate engagement include continuity of care and the therapeutic relationship. A review by O'Brien et al[381] found that approximately 30% of service users with mental health needs drop out of contact with services. Kreyenbuhl et al[379] reported rates of treatment dropout among individuals with serious mental illnesses to range from 16 to 67%, depending on the sample and how disengagement was operationalized. Correlates of disengagement include younger age, ethnic minority status, comorbid substance abuse, low social functioning, and social isolation. Treatment dropout is especially high during the initial period of treatment.[379] A number of reviews have attempted to identify reasons for disengagement. As reported by consumers, reasons include unsympathetic providers, not being listened to, not being able to actively participate in decision making, being dissatisfied with services,[381] a desire to be independent, and loss of control due to medication effects.[382]

Motivational interviewing (MI) is both an approach and a set of techniques to assist individuals in resolving ambivalence and committing to a behavioral change.[383] Initially developed for increasing engagement in substance-abuse treatment, MI has been studied among those with comorbid substance-use disorders and serious mental illnesses. Outcomes reported in those studies, however, have generally been limited to mental health and substance use rather than engagement.[384] There has been surprisingly little investigation of the use of MI or other motivational enhancement techniques to enhance or promote engagement in the broader population of individuals with serious mental illnesses. When MI strategies have been implemented in this population, they have generally been used to enhance outcomes for behavioral health targets, such as weight loss for individuals taking antipsychotic medications[385] or smoking cessation.[386] In a meta-analysis of MI across varying populations, Lundahl et al[387] identified 34 studies that measured treatment engagement as an outcome of MI. MI showed a 5–15% advantage over no treatment and a slight but not significant advantage over other viable treatments. These heterogeneous studies, while not limited to samples of individuals with serious mental illnesses, nevertheless demonstrate the potential of MI to enhance engagement. Further investigation in this area is warranted.

In related work, Kreyenbuhl et al[379] summarized empirically supported interventions and those with promise for increasing engagement in mental health services. They cited research support for low-intensity interventions focused on system facilitators such as appointment reminders, priority outpatient appointments after hospitalization, and outpatient engagement during hospitalization. Also supported are medium-intensity interventions, such as critical time interventions to strengthen individuals' ties to service providers and social networks during times of transition,[388] and high-intensity interventions such as ACT and Intensive Case Management (ICM) for those at highest risk of failing to engage.[389] Assessing cultural context also has the potential to improve engagement, both by attending to each individual's social setting and by recommending services that are consistent with and acceptable to the individuals in their settings.[390]

It is increasingly recognized that many individuals who discontinue services do so because they are not involved in decision making, do not feel listened to, and are dissatisfied with services. In response, recommendations have been made to develop partnership[382] and self-determination treatment models that emphasize shared decision making, reduction of community barriers to self-determination, education of stakeholders, modification of legislation that restricts empowered decisions, and streamlining of interventions to ease participation.[62]

A recent review by Curtis et al[64(p15)] cited evidence that people with serious mental illnesses generally have a greater desire to be actively involved in treatment decisions than those in general medical settings and are especially interested in decisions related to use of psychiatric medications. The authors emphasized that shared decision making is "especially useful when more than one viable option exists, when there is a conflict about which option is 'best,' or when outcomes are dependent on acceptance and follow-through by the person using the treatment or services," a common situation in mental health care delivery. They identified three essential components for effective shared decisions: information and preparation for making a decision, the interactive process of discussing and generating a shared decision, and systematic opportunities to review and revise decisions after they are made. However, despite the relevance of shared decision making to mental health treatment, few studies have been conducted with these populations and in these settings.

Summary and Implications Rates of failure to engage in mental health services are understudied, as are the reasons for such failure and interventions to promote engagement and prevent disengagement. Research is needed to determine appropriate outreach strategies that are consistent with and respectful of the preferences of those outside the service system, as well as strategies that retain the engagement of those within the system who desire continued care. There is incipient support of patient-centered care interventions that encourage activation, empowerment, and shared decision making as means of attracting and sustaining individuals in care. It should be noted, however, that a primary mission of patient-centered care is to honor individual preferences, which at times includes respecting decisions to forego care.

Therapeutic Relationship/Working Alliance The degree of alliance between provider and service user within a therapeutic relationship is widely acknowledged as an important nonspecific component of the care delivery process. There is both qualitative and quantitative evidence that positive relationships facilitate engagement in services and, over time, foster recovery[52,382] for individuals with serious mental illnesses. In a meta-analytic review, Martin et al[391] found evidence that working alliance was moderately associated with conventional psychotherapy outcomes, although only 23% of the studies reviewed included service users with serious mental illnesses. Moreover, psychotherapy treatment settings are quite different from those in which individuals with serious mental illnesses commonly receive treatment. Priebe et al[57] conducted a systematic review and identified nine studies that prospectively tested association of therapeutic relationships with outcomes (functioning, symptom level, and hospitalization) in studies of individuals with schizophrenia spectrum disorders. Due to the small number of available studies and the heterogeneity of methods used, the authors were unable to conduct the planned meta-analysis, concluding that evidence for the predictive value of the therapeutic relationship for treatment outcomes in this group is limited.

Summary and Implications Existing reviews of the association between the working alliance or therapeutic relationship and outcomes underscore the need for methodologically rigorous research on working alliances using measures validated for use among people with serious mental illnesses. Measuring these relationships at baseline and over time, linking them to patient-centered outcomes, and considering mediators of these relationships could provide the information necessary to understand how these relationships affect engagement and outcomes.

Continuity of Care Over Time and Across Care Settings, Services, and Providers In addition to solid engagement and development of a strong working or therapeutic alliance, continuity of care is considered one of the essential components of high-quality care, particularly in the treatment of chronic and relapsing conditions. Its definition, however, has changed over time with the changing health care system and the advent of consumer empowerment, and its relationship to other concepts such as coordination of care, integrated care, and case management is unclear.[392] Gulliford et al[393] identified two meanings of continuity of care: as a "continuous caring relationship" over time and as "seamless service" over time and across services, organizations, and care settings. A comprehensive review by Haggerty et al[394] elaborated on this definition to include three dimensions of continuity: informational (availability of information on past care events and personal information), management (consistency of approach to caring for the service user in a manner responsive to the user's changing needs), and relational (ongoing relationship between service user and a care team). Contact continuity—regular and consistent contact with a service continuum—is a fourth dimension that has been included by some researchers.[395]

A strong case has been made that continuity of care is even more essential in the care of those with serious mental illnesses than those with other chronic conditions, due both to the necessarily increased complexity of the service system[394] and to illness-related individual characteristics that may interfere with consumers' ability to provide comprehensive information about treatment during acute episodes when treatment history may be most important.[52] Given the importance placed on continuity of care by major health policy institutes in Britain, the United States, and Canada, there is a surprising lack of consistency in defining the concept. Moreover, the lack of consensus around a set of standardized measures, despite repeated calls for such development over the past two decades, is surprising.[394,396,397] Addressing these deficits would allow for thorough evaluations of the effects of different types of continuity of care on individual outcomes and would facilitate the development of interventions to improve those found to be most important.[394,395]

Given the difficulty in defining the term and distinguishing it from overlapping concepts, it is similarly difficult to summarize the impact of continuity-of-care interventions on service user outcomes. In primary care, improved performance on related concepts (coordination of care, integration, patient centeredness) is related to better quality of care, better health, and lower cost at both individual and population levels.[392] For those with serious mental illnesses, the vast majority of research is observational and examines associations between continuity of care and a wide range of outcomes—costs, utilization, engagement in treatment, coordination of care, recovery, QOL, and symptoms. Crawford et al[397] reviewed the evidence for factors influencing continuity of care using several measures. They found that a number of service user characteristics relate to withdrawal from treatment, including ethnic minority status, unemployment, social isolation, and lower socioeconomic status. This review found that information sessions and consumer training provided during inpatient stays, as well as visits by outpatient staff, improved follow-up outpatient care. They also found that interventions designed to improve continuity of care, including ACT, case management, and community mental health teams, reduced rates of treatment withdrawal for up to 24 months. A Canadian study[398] found that higher continuity, as rated by both observers and service users, was associated with better general and disease-specific QOL and service satisfaction. A cost analysis for this same study found that observer-rated continuity of care was associated with lower hospital cost but higher community cost, with no statistical difference in total costs.[399]

The importance of incorporating service user views on continuity of care has been repeatedly emphasized.[393] Green et al[52] found that relational continuity combined with recovery-oriented, consumer-directed care was related to increased satisfaction with care, fewer psychiatric symptoms, better recovery outcomes, and enhanced QOL.

Summary and Implications Continuity of care is a multidimensional concept that has been neither clearly defined nor differentiated from related concepts. As emphasized by most reviews, there is a great need to develop widely accepted definitions of continuity of care and its multiple dimensions, as well as to develop standardized patient-centered measures of continuity-of-care components that incorporate the values and voices of people with serious mental illnesses. There is a need to use such measures to examine the extent to which they relate to consumer-preferred outcomes, and to compare the effectiveness of different interventions designed to increase continuity of care. Concepts of continuity of care are highly emphasized in both national and state health reform efforts. This increases the urgency of the development of good measures in order to evaluate the impact on outcomes for those with serious mental illnesses and to evaluate the delivery system itself.

Providing Education and Information Education and information are considered important aspects of care, particularly in the context of chronic conditions. As noted elsewhere in this report, the prevalence of comorbid chronic medical problems among those with serious mental illnesses suggests that this population's educational and informational needs are both multifaceted and substantial. Formal psychoeducation programs tend to be broad, covering information about diagnoses, anticipated course, symptoms, and available psychiatric and psychosocial treatment options and their corresponding benefits and risks. These programs can also be narrow, however, focusing on specific aspects of illness management such as medication (eg, optimal dose, side effects, importance of adherence) or specific wellness strategies (eg, sleep hygiene, diet, physical activity). In a review of illness management strategies, Mueser et al[400] found that providing broad-based psychoeducation increased individuals' knowledge about mental illness but did not affect symptoms, social functioning, using medication as prescribed, rehospitalizations, or relapses. Similarly, the authors found that providing specific medication-related psychoeducation increased knowledge about medication, but they found little evidence that it affected other outcomes studied. Despite the lack of effect of such programs on clinical outcomes, the authors assert that gaining knowledge is essential to making informed decisions about treatment. They concluded that psychoeducation, when provided as a component of an illness management program that includes behavioral tailoring for medication, coping skills training, and training in relapse prevention, is recommended for individuals with serious mental illnesses.[400,401] A more recent review of psychoeducation for schizophrenia found that didactic psychoeducation interventions delivered individually or in groups improved both clinical and patient-centered outcomes. Psychoeducation improved medication adherence, reduced rates of rehospitalization (and length of stay) and relapse, improved social and global functioning, and increased satisfaction with treatment.[402] The trials included in these reviews predominantly included individuals diagnosed with schizophrenia. Rouget and Aubry[401] reviewed the efficacy of psychoeducational approaches used to treat bipolar disorder and similarly concluded that increasing knowledge through psychoeducation, particularly as part of a more complex intervention, decreases risk of rehospitalization and relapse through improved treatment adherence that resulted in improvements in illness course—a very important patient-centered outcome.[401]

Formal psychoeducation programs have been developed to provide education and information to both individuals with mental illnesses and their families. Family psychoeducation is recommended for individuals with serious mental illnesses,[140] particularly for those with a recent exacerbation of illness, based on findings that family psychoeducation interventions of sufficient duration (optimally 6–9 months) significantly reduce rates of rehospitalization and relapse, improve treatment adherence, reduce perceived stress, and produce better vocational outcomes—important outcomes for patients as well as their families.

Educational efforts can be as limited as informing people about their particular diagnoses, or as broad as those targeting improved health and wellness by simultaneously providing education and information about both mental and physical health conditions.[403] A recent review of lifestyle interventions for individuals with serious mental illnesses found that manualized programs with a combined activity and education approach were most likely to be effective and improve mental health status and QOL, while programs focused on general wellness or only on health promotion education were less successful.[404]

Summary and Implications It appears that providing psychoeducation to individuals and families increases knowledge and positively influences clinical outcomes. Access to information about mental illness is crucial to individuals' ability to make informed decisions about their care, and being informed may be an important patient-centered outcome. If that is the case (and researchers should address this question), education for individuals should perhaps be considered as ends in addition to means. That said, the effects of providing education and information on engagement and therapeutic alliance remain to be investigated, as do their effects on patient-centered outcomes.

Trauma-Informed Care The impact of trauma can be profound in terms of negative effects on health, mental health, social functioning, and well-being, particularly when individuals have experienced multiple incidents or intentional interpersonal violence.[405] The influential Adverse Childhood Experiences study[406] showed a strong, graded relationship between a number of categories of adverse childhood events (psychological, physical, sexual abuse; emotional and physical neglect; marital discord; violence against mother; living in household with substance abuse or mental illness; or ever imprisoned) and each of numerous adult health risk behaviors (smoking, severe obesity, physical inactivity, depressed mood, suicide attempts, alcoholism, any drug abuse, greater than 50 sexual partners, and a history of having a sexually transmitted disease). Despite this evidence, the mental health and substance-use service delivery systems historically have not fully considered the effects of trauma history on treatment and outcomes. Most service users with trauma histories have not been screened for, nor do they carry (when appropriate), a primary diagnosis of posttraumatic stress disorder (PTSD).[405] Thus, implications of past trauma and opportunities for appropriate intervention are missed, and those meeting PTSD criteria are often not provided with the evidence-based interventions for that disorder.[407,408]

As the association between experiences of trauma and subsequent psychiatric illness and substance misuse is increasingly recognized, especially in the publicly funded mental health and substance-abuse treatment systems,[405] "trauma-informed care" is emerging as an important area for further study. Rates of trauma history in these populations may be as high as 90% or greater.[409–411] There is also a high frequency of individuals with serious mental illnesses and trauma histories in the correctional system,[412] where rates of sexual and other violence are significantly greater among prisoners with mental illness compared with those without such illnesses, and where traumatic victimization has increasingly been identified as a major problem.[413,414]

The push to adopt trauma-informed care as a framework for all behavioral health treatment appears to be driven primarily by the consumer movement and the publicly funded mental health service system. Between 2001 (when 12 states formed a network to share ideas about improving the service system to better screen for trauma and to address its sequelae) and 2009, the number of states with explicit trauma-related activities (eg, mission statements addressing effects of trauma and corresponding policies and guidelines) grew to 44. In 2005, SAMHSA supported the development of a National Center for Trauma-Informed Care. These and other major policy and advocacy activities undertaken by SAMHSA and NASMHPD are reviewed in a 2008 technical report entitled "Models for Developing Trauma-Informed Behavioral Health Systems and Trauma-Specific Services."[405] In 2011, SAMHSA continued to emphasize trauma as a strategic focus of the agency, advocating for a public health approach to trauma and for the screening, early intervention, and treatment of trauma as a common practice in health, behavioral health, social service, and criminal justice systems.[415]

Those advocating for a transformation of mental health care envision a system "in which all components…have been reconsidered and evaluated in the light of a basic understanding of the role that violence plays in the lives of adults, children and adolescents, and families or caregivers…[The system] accommodates the vulnerabilities of trauma survivors and allows services to be delivered in a way that will avoid inadvertent re-traumatization and will facilitate consumer participation in treatment."[405] It is a system that embeds a set of core values throughout the organization and all clinical interactions, including emotional and physical safety, trustworthiness, consumer choice and control, collaboration between service users and providers and among agencies and systems, treatment planning, and building of empowerment skills.[416]

Given the prevalence of activities to advance trauma-informed systems of care, the lack of studies that systematically test the effects of such care is surprising. Some of the core principles of trauma-informed care (eg, collaboration and consumer choice) have been shown to be important characteristics of service systems independent of trauma-informed principles, as discussed elsewhere in this report. One pre-post study evaluated the effect of implementing NASMHPD's six core strategies for improving trauma-informed care on the use of seclusion and restraint in a child and adolescent hospital, and showed a modest reduction in events. Outcomes were measured for only 6 months, however.[417]

While there has been little evaluation of systems interventions to promote trauma-informed care, there is considerable evidence on trauma-specific services. A recent Cochrane review[418] of psychological treatments of PTSD found strongest support for trauma-focused cognitive behavior therapy including exposure, with immediate and follow-up benefits (compared with wait list or usual care) on clinician-rated and self-reported traumatic stress symptoms, depression, anxiety, and PTSD diagnosis after treatment. Stress management and eye movement desensitization and reprocessing were also effective in improving most measures, compared with usual care and wait list. Interestingly, in contrast to trauma-focused cognitive behavior therapy, neither of these latter interventions demonstrated effectiveness on self-reported stress symptoms.

Integrated Care for PTSD and Substance-Use Disorders Two recently published systematic reviews of integrated[419] and concurrent[420] treatment of co-occurring PTSD and substance-use disorders concluded that integrated or concurrent treatments were effective in reducing substance use, PTSD, and other mental health symptoms and that these effects lasted at follow-up periods. Neither integrated nor closely coordinated concurrent interventions showed superior results over nonintegrated sequential interventions, however. Both reviews identified significant weaknesses in study methods and the need for rigorous RCTs and emphasized the importance of long-term follow-up for future research.

Trauma and PTSD in Adults With Serious Mental Illnesses Adults with serious mental illnesses have higher rates of interpersonal violence history than the general population, with reported rates ranging from 49% to 100% in study samples, including high rates of childhood sexual abuse (median across studies = 34%), childhood physical abuse (53%), adult sexual assault (38%), and adult physical assault (77%).[421] Mueser et al[411] found that 43% of service users with serious mental illnesses being treated in the public mental health system experienced PTSD, but that very few of those (less than 3%) had the diagnosis listed in their chart. Traumatic experiences and PTSD diagnosis are associated with poorer clinical functioning and increased health care utilization in this population. In addition, a recently published review of PTSD in adults with serious mental illness[421] established that, similar to the general population, interpersonal violence history and diagnosis of PTSD is correlated with substance abuse and other psychiatric disorders, homelessness, impaired functioning, poorer QOL, and increase in risk and self-harm behaviors. Unfortunately, there is a high rate of failure to identify trauma history and PTSD diagnosis among individuals with other serious mental illnesses, leading to failure to provide appropriate evidence-based treatments. These histories also result in higher health care utilization and costs.

Few rigorous trials have been conducted on the effects of PTSD interventions among individuals with PTSD and other serious mental illnesses, largely because of concerns among clinicians that such interventions would exacerbate symptoms. Cognitive behavioral therapy (CBT), however, has been shown to be beneficial in the treatment of schizophrenia without exacerbation of symptoms, and the few RCTs that have been conducted with a focus on PTSD have demonstrated beneficial effects.[421] Mueser et al[422] conducted an RCT of CBT treatment of PTSD with 108 patients with a major mood disorder or schizophrenia and found outcomes superior to treatment as usual over a 6-month period. Due to concerns over patient tolerability, their intervention did not use exposure as a core component. Recently, Lu and colleagues (2012) demonstrated that community providers could be trained to deliver CBT for PTSD with high fidelity in this population. Despite its demonstrated efficacy in general populations, few studies have examined exposure-based therapy in populations with serious mental illnesses, due to concerns over symptom exacerbation. However, a tantalizing open pilot trial of a multicomponent intervention that included exposure treatment found significant reductions in PTSD symptoms and anger, and improvement in mental health functioning and quality of social relationships.[424]

Summary and Implications The well-established relationship between trauma—especially ongoing interpersonal violence—and psychiatric symptoms and functional impairment has led to broad demands to develop trauma-informed systems of care. However, the basic parameters of trauma-informed care are inadequately defined to allow testing of the effectiveness of such care system transformations. Research on trauma-informed care is in its infancy, key components of trauma-informed care need to be defined, and rigorous intervention trials are needed.

Trauma-specific treatments focused on addressing chronic PTSD, on the other hand, have a significant evidence base demonstrating the comparative effectiveness of interventions. Even here, however, more well-controlled trials are needed to test their effects among individuals with other serious mental illnesses. It is important that such trials explicitly evaluate the immediate and long-term impact on symptoms other than PTSD symptoms, including potential harms, drop-out rates, and potential positive changes in psychological growth and healing.[407]

Despite the evidence supporting exposure-based therapies, few clinicians use these interventions in their treatment of clients with PTSD, believing that such interventions are contraindicated.[407] Moreover, a relatively high percentage of clients receiving treatment for trauma sequelae drop out or continue to meet PTSD criteria following treatment. Studies are needed evaluating the effectiveness of specific treatments related to service user characteristics, and testing effective means of training and disseminating evidence-based interventions to general mental health practitioners. Finally, integrated treatment of trauma-specific mental health interventions with substance abuse treatment is another area that has been identified as needing more comparative effectiveness trials to examine the effectiveness of different models of integrated care.[420]

Peers as Providers and Supporters of Care and Services There is a growing literature examining consumer- or peer-led care and service provision as an alternative or complementary adjunct to professional care, based on the belief that individuals who are successfully living with serious mental illnesses can provide important understanding, support, experience, and advice to others with these disorders.[425,426] In addition, peer support groups are thought to be mutually beneficial. Many of these relationships occur informally, but efforts have increasingly focused on developing peer-run mutual support programs (eg, the Hearing Voices Network, http://www.hearing-voices.org) and on training peers to serve as providers of more traditional services. While evidence for the effectiveness of peer-led models of care and service delivery is limited, inconsistent, and uses varied outcome measures, it suggests that, at minimum, trained peers produce outcomes similar to those produced by professionals. In a recent review, Repper and Carter[426] reported evidence from two studies that confirm no difference was found in hospital admission rates or length of stay when peers provided treatment, compared with treatment provided in usual care, while another study demonstrated longer community tenure among individuals assigned to peer support workers, compared with those assigned to usual care. Because of the scant availability of RCTs evaluating the impact of employed peer support workers, these authors extended their review to include nonexperimental designs that allowed a more complete picture of potential benefits of services provided by peers. From this literature it appears that peer support workers may actually be *more* successful than professionals at promoting hope and belief in recovery; encouraging empowerment; and increasing engagement, self-esteem, self-efficacy, self-management, social inclusion, and social networks. There also appear to be benefits for the peer support workers themselves, including those mentioned above as well as the opportunity for disclosure and meaningful, valued work in a supported context.

Summary and implications. There is a clear need to establishing an evidence base for the effectiveness of peer-supported services. Future research requires RCTs and CER that compare consumer-led models applied in varying ways (eg, as adjunctive to care or as an engagement strategy) with traditional services and as stand-alone services.

Unintended Consequences and External Influences While involving peer support workers in broader care and service delivery models may produce many benefits, the impact on the peer support worker must be considered as well. Where accountability and boundaries begin and end may be less clear with peer support workers compared with professionals, warranting continuous attention to the cumulative effects of vicarious stress and trauma. That said, there is currently no evidence suggesting that peer-support models harm peer-support workers.

Care and Service Packages for Specific Subpopulations. It is beyond the scope of this report to review the evidence for the myriad mental health care interventions and service packages delivered in usual-care practice settings. We have, however, reviewed service packages targeting specific populations in an effort to identify population-specific key leverage points in the mental health system.

Justice-Involved Individuals Individuals with serious mental illnesses are disproportionately represented in the criminal justice system. Although prevalence estimates vary and it is widely recognized that most estimates are likely underrepresentative of actual prevalence rates, a meta-analysis of 62 surveys from 12 countries found that 14% of offenders suffer from at least one major mental illness.[427] Applying this figure to the most recent published census data from the Bureau of Justice Statistics[427] yields an estimate of nearly 700 000 adults with serious mental illnesses under correctional supervision. In a recent study by the Vera Institute of Justice[428] that combined data from five criminal justice and mental health agencies in the Washington, D.C. area (2 874 individuals), the authors found that many of those arrested with mental health needs were not known to community mental health providers. Most (83%) were known to at least one criminal justice agency during the study period, yet the Department of Mental Health knew of only 59% of those. Of the 666 cohort members with mental health needs who came into contact with the justice system, 46% were not identified as having a mental health need and 33% of arrestees known by the Department of Mental Health to have a psychotic spectrum disorder were not identified by any of the criminal justice agencies. Identification rates were even lower for individuals with other diagnoses (eg, anxiety, depression). This report brings attention to the problem of underrecognition of mental illness by service systems but also highlights potential opportunities for cross-agency coordination. The authors provide recommendations for improving identification through targeted information-sharing initiatives, increasing interagency communication, expanding strategies for engaging underserved groups, and linking individuals with providers across agencies.

Early identification of mental illness and appropriate service provision should be important goals of the criminal justice system because offenders with mental illness are more likely than those without these disorders to fail under correctional supervision (ie, have their parole or probation revoked or suspended), and twice as likely to return to prison within 1 year of release.[429] Despite recognition of this troubling situation, interventions to identify and serve justice-involved individuals with serious mental illnesses have not yet demonstrated any meaningful reduction in the overrepresentation of such persons in the justice system.[33]

Criminal justice models include diversion from the jail system, mental health courts, specialty mental health probation or parole, jail aftercare, and community reentry programs. Mental health models include Forensic

Assertive Community Treatment and Forensic Intensive Case Management. These interventions are well-described elsewhere.[33] They have in common their focus on provision of psychiatric services (frequently in the community, as most individuals eventually enter parole or probation) with the goal of reducing recidivism.

There is a dearth of empirical outcome research to support these interventions. What little research exists has focused almost exclusively on criminal justice outcomes to the exclusion of mental health outcomes, and is limited by serious methodological issues. In their meta-analysis of 37 effect sizes from 25 studies assessing the effectiveness of interventions for justice-involved individuals with a mental illness, Martin et al[430] tentatively concluded that these interventions were modestly effective in reducing criminal justice involvement but had no significant effects on mental health service use, medication use, or mental health outcomes. In contrast, Morgan et al[431] synthesized treatment effects of interventions on criminal recidivism (ie, return to the criminal justice system) and psychiatric recidivism (ie, placement in a psychiatric hospital), finding strong positive treatment effects on general mental health symptoms and coping, and moderate effects on institutional adjustment and behavioral functioning. Mean effect sizes for criminal and psychiatric recidivism were inconclusive, however, and the review was limited by the quality of available research and limited numbers of RCTs.

In another review of contemporary interventions for justice-involved individuals with serious mental illnesses, Skeem et al[429] found no support for the presumed link between symptom control and reduced recidivism,[432] a prevailing belief that has shaped the development of many of these interventions but has scarcely been tested. These authors suggest instead that the relationship between mental illness and criminal behavior, in most cases, is fully mediated by a third variable (eg, poverty, social learning) that establishes and maintains criminal risk factors. They further suggest that these findings demonstrate that traditional services are not the sole solution, and they argue for the design of a new generation of person-centered services tailored to the actual (rather than perceived) needs and risks of justice-involved individuals with serious mental illnesses. For example, there is emerging evidence that offenders with mental illness are equivalent in their criminal thinking[431] and antisocial attitudes[412] compared with nonmentally ill offenders. This suggests that in addition to their mental health needs, justice-involved individuals with serious mental illnesses have needs related to criminogenic characteristics that must be addressed. Interventions that treat co-occurring issues of criminality and mental illness remain a significant deficit. Another explicit and well-documented need among a substantial majority of these individuals is substance-abuse treatment.[11] Additionally, and not unrelated for many, there is an evident need for trauma-based services and treatment. Wolff and Shi[433] found a significant relationship between trauma history and both addictive behaviors and criminal involvement.

Summary and Implications Consistent with the policy focus of the criminal justice system, research focusing on interventions to serve justice-involved individuals has concentrated primarily on criminal recidivism as an outcome, with mental health outcomes secondary. These interventions appear to influence criminal recidivism only modestly at best. While they may influence immediate mental health outcomes, there is no clear evidence that they influence psychiatric recidivism at all. Further, while it is widely believed that improving mental health outcomes will reduce criminal recidivism, this approach has been shown to be oversimplified, and there has been a call to redesign patient-centered interventions for justice-involved individuals to address the heterogeneity of criminogenic, mental health, substance-abuse, and trauma needs.

Unintended Consequences and External Influences Justice-involved individuals with mental illnesses are often presented with an array of programs that, taken together, risk causing difficulties because their goals are not necessarily compatible. In addition to the lack of evidence that "polyprogramming" is effective, such programming may be neither cost-efficient nor helpful when resources are limited.[33]

Individuals With Comorbid Substance Abuse Individuals with serious mental illnesses are at greater risk of developing alcohol- and drug-use disorders, with rates of substance abuse or dependence estimated at between 40% and 70%.[351] These substance-related problems contribute substantially to early mortality in this population,[351] and individuals with serious mental illnesses are also at higher risk of adverse psychiatric, social, and medical consequences from even moderate use.[384,434] Higher risks of medical comorbidities and premature mortality likely result from a convergence of many factors, including increased incidence of harmful behaviors, toxic effects of substances, and unintended interactions with psychoactive medications.[435] Medical care that is more sporadic or of poorer quality compounds this risk and is related to poorer access to care, increased rates of poverty, unemployment, lack of insurance, discomfort of primary care providers regarding treating individuals with serious mental illnesses, and lack of coordination between the general medical system and the behavioral health specialty care system with primary responsibility for treating the psychiatric illness.

People with serious mental illnesses and co-occurring substance-use disorders have less motivation to change, are harder to engage, drop out of treatment programs at higher rates, and make slower treatment progress than individuals with substance-use disorders but no other mental disorders.[436] Studies of psychosocial interventions designed to treat this population consistently report high rates of attrition and relapse. Not surprisingly, given problems with engagement and treatment dropout, evidence for the effectiveness of these treatments is inconsistent. A 2008 Cochrane Review found little compelling evidence to support one treatment over another,[437] although the same group conducted a later systematic review[384] using more liberal study inclusion criteria and found that MI had the best evidence for reducing substance use over a short period of time and, when combined with CBT, also had positive effects on mental state. The few studies that incorporated contingency management also showed potential to reduce substance use and, when combined with MI and CBT, to increase retention in treatment. The support for CBT alone was inconsistent, although the length of CBT treatment and the underlying diagnosis (schizophrenia or bipolar disorder) may moderate effectiveness. Finally, long-term integrated residential treatment programs also showed some positive effects on reduced substance use.

Consensus recommendations for the treatment of people with both serious mental illnesses and substance-use disorders by an expert panel of academic and state mental health system experts were published in 2005.[434] They called for programs that integrate addiction treatment with psychiatric treatment that includes MI, relapse prevention, 12-step facilitation, and case management—especially during vulnerable periods—to help the individuals navigate services and remain in treatment. Drake et al[438] reviewed evidence for integrated models of care for dually diagnosed individuals and found promise in programs that provided comprehensive integrated care that included MI, assertive outreach, medication management, skills training, and individual and group substance-abuse counseling for service users and families.

Druss and von Esenwein[435] conducted a systematic review of interventions designed to improve medical care for persons with mental and addictive disorders (but not specifically those dually diagnosed). They found six RCTs that spanned a continuum of approaches to improving medical treatment, ranging from facilitated referrals to primary care to team-based care to colocation of medical consultants within specialty mental health settings. Three of the six studies examined inpatient or residential treatment programs, and the primary comparison was referral to primary care. Compared with this common but relatively basic comparison intervention, they found that linkages to primary care were better in the intervention groups (five of six studies) and that the interventions resulted in improved process measures of medical quality (five of five). In terms of medical outcomes, however, results were mixed. Overall, they found that the interventions were cost neutral.

Summary and Implications There is ample opportunity to improve psychosocial interventions and quality of medical care for those with serious mental illnesses and substance-use disorders. In particular, models of integrated care need to be examined, including integrating general medical care into specialty care settings. Testing is needed on a range of approaches that vary based on diagnostic populations, local and state policy and funding characteristics, and overall resources available.

Unintended Consequences and External Influences There continue to be funding and structural barriers to coordinated and integrated services for the treatment of persons with both serious mental illnesses and substance abuse and dependence. These barriers necessitate collaboration and coordination among different governmental agencies and funders at the federal, state, county, and local levels. In addition, as the Medicaid population expands under the ACA, it will be important to monitor whether benefits are reduced and whether integration inadvertently results in reduced rehabilitative and recovery services for people with serious mental illnesses. State efforts to reorganize care in response to the ACA, by using medical or mental health homes and Accountable Care Organizations, should provide interesting opportunities to study different forms of integrated care.

Individuals Desiring or Prescribed Medications Psychopharmacologic treatment of all serious mental health disorders has long been standard practice. A great deal of research has led to the development of treatment algorithms and practice guidelines,[149,322,439–442] yet studies have shown that there are continuing deficiencies in the quality of medication prescribing,[149] suggesting that clarified recommendations are insufficient to improve medication-based treatment of serious mental illnesses.[443]

Research on consumer perspectives regarding medication guidelines could shed light on failed implementation and lack of adherence,[444–446] but we know very little about what individuals with serious mental illnesses want with respect to their medications. Instead, a great deal of clinical research has focused on the problem of medication nonadherence (often pejoratively termed "noncompliance")—the prevailing explanation for why people with these diagnoses have low rates of participation in EBPs.[62] Experts have identified factors associated with nonadherence, including believing medications are no longer needed, poor insight, distress associated with specific side effects (eg, sedation among people with bipolar disorder, or weight gain among people with schizophrenia),[445] general fear of medication side effects, and inadequate efficacy with persistent symptoms.[447] As a potential solution to this problem, researchers have tested supplementing medication with psychosocial interventions, including CBT, Family Based Services,[149,448] Cognitive Adaptation Training, and ACT,[446] and have found these to increase adherence[446,449] while simultaneously addressing functional symptoms not managed by medications.[446,450,451] However, to our knowledge, research addressing consumer perspectives on medication adherence and how it relates to psychosocial services is largely absent and much needed.

Corrigan et al[62] call for a paradigm shift away from the current value-based perspective that people who do not opt for prescribed treatments are flawed or otherwise symptomatic (and, implicit in that assumption, require more aggressive motivation for compliance) toward a self-determination framework where treatment decisions truly allow choices, including those that are ultimately the "wrong" choices (ie, those that may not lead to health, wellness, or the achievement of patient-defined goals). In the era of PCOR opportunities, moving away from the traditionally paternalistic focus on nonadherence toward empowering consumers in a shared process of treatment negotiation and planning may be more in line with what consumers want and may better help those who choose to take medications take them more effectively.

Individuals Who Do Not Want to Take Psychiatric Medications Problems with adherence and discontinuation of prescribed psychiatric medications are among the most common complaints lodged by mental health clinicians about their patients. Significant negative side effects, including movement disorders, weight gain, and metabolic problems, combined with inadequate symptom control and sedation, suggest that service users have logical reasons for reducing or eliminating their use of medications.[445] The growth of online information sources outside the service system (eg, http://www.alternativementalhealth.com/directory/search.asp) that provide support for people wanting to avoid or discontinue psychiatric medications suggests that this is an area in need of attention by mental health researchers.

Although rare, some mainstream alternatives have been proposed for people who do not want to take medications or who prefer to limit their use of medications as much as possible. These include antipsychotic postponement (for those recently diagnosed who may experience spontaneous remission),[452] dose-reduction or low-dose medication strategies,[452] and noncontinuous targeted treatment.[453] These strategies are more likely to be employed by alternative programs such as those based on the Open Dialogue (OD)[454,455] or Soteria models.[456,457]

Evidence exists for antipsychotic postponement, particularly when paired with psychosocial interventions.[452] In one study of targeted treatment,[452] course of illness (including rehospitalization rates) was similar for those receiving continuous and those receiving noncontinuous targeted medication when those in the targeted drug arm of the study also received enriched psychosocial clinical care and early intervention. In another study, however, individuals diagnosed with recent-onset schizophrenia had similar relapse rates regardless of study arm, but those characterized as having multiple episodes in the targeted treatment arms had much higher relapse and rehospitalization rates than those in the maintenance arm.[458] The most recently published treatment recommendations from the Schizophrenia Patient Outcomes Research Team[149] do not endorse a targeted treatment approach, but concede that for select individuals diagnosed with recent-onset schizophrenia who refuse continuous maintenance pharmacotherapy, or for whom some other contraindication exists, targeted treatment is an alternative. They counsel, however, that it should be pursued only when the individual can be monitored closely enough that the targeted intervention can be initiated at the earliest signs of clinical exacerbation.

Beyond the studies described above, and those examining the effects of short-term medication withdrawal or medication "holidays," we were unable to find recent evaluations of programs that provide services specifically to individuals who do not want to take medications. If services are to become patient centered and successfully engage all individuals with serious mental health problems, programs focusing on alternatives to medications need to be developed for those who prefer to limit medications or are unwilling to use them.

Overweight Individuals Over 42% of adults with a serious mental illness are obese, due in part to adverse effects associated with antipsychotic medications.[90] Moreover, fewer than 20% of people with schizophrenia engage in regular moderate exercise, and people with schizophrenia tend to have poorer diets than the general population.[404] Modest weight loss (5% or greater) results in clinically significant reductions in cardiometabolic risk, and a growing literature compares the effectiveness of various interventions aimed at improving diet, reducing weight, and increasing physical activity. Bartels and Desilets[404] conducted a systematic review and analysis of this literature, concluding that lifestyle interventions have been inconsistently effective in producing clinically significant weight loss and that effective interventions have succeeded in only a minority of participants. The factors driving success in such programs remain unclear, but programs are more likely to succeed if they last 3 months or longer and incorporate both education- and activity-based approaches. The Schizophrenia Patient Outcomes Research Team[141] recommendations suggested that overweight individuals diagnosed with schizophrenia be offered a psychosocial weight loss intervention that is at least 3 months in duration and focuses on psychoeducation and nutritional counseling, caloric expenditure, portion control, behavioral self-management, goal setting, regular weighing in, self-monitoring of diet and physical activity, and modification of diet and physical activity. In addition to the potential weight loss benefits of these interventions, evidence reviewed in this report[141] suggested that providing early behavioral intervention to individuals recently diagnosed with serious mental illnesses, or new to antipsychotic medications, can prevent greater weight gain compared with controls not receiving psychosocial intervention.

In addition, there is an urgent need for the development of medications that are not associated with weight gain and other side effects.[459] In the absence of such agents, additional research comparing approaches to preventing and managing antipsychotic-associated weight gain is needed,[439,445,460] particularly given the high rates of medication discontinuation and the differential side-effect profiles in existing comparative effectiveness studies.[459,461]

There is an important emerging literature on the efficacy of various adjunctive medications that, when used in combination with antipsychotics, attenuate antipsychotic-related weight gain and metabolic abnormalities. Numerous studies have examined the efficacy of adjunctive Metformin in prevention and treatment of antipsychotic-induced weight gain, with results supporting its use,[462–464] particularly with first-episode or drug-naïve patients and in combination with lifestyle intervention.[465] Sibutramine and topiramate have also shown some benefit, while amantadine and orlistat appear less effective and less tolerable.[460] More research of this nature is needed, as well as a better understanding of the risks of weight gain when patients are taking multiple psychiatric medications together (each with its own and perhaps additive effects on weight).[466] Finally, further study of the pharmacogenetics that influence response to antipsychotic medications may inform personalized medicine that limits weight gain.[466–468]

Unemployed or Underemployed Individuals Interested in Working Because the onset of serious mental health problems typically occurs in adolescence and early adulthood, these disorders have the potential to affect educational attainment, employment, and earning potential.[469] Despite such barriers, most people with serious mental illnesses want to work,[470] and evidence shows that paid employment can improve a wide variety of patient-centered and other outcomes, including service use and costs.[471–473]

Supported employment (SEm) is widely acknowledged as an EBP for individuals with serious mental illnesses. The Schizophrenia Patient Outcomes Research Team[140] recommends that SEm be offered to any person with schizophrenia who expresses an interest in working. The review group found no evidence to support concerns that engagement in SEm leads to increased stress, exacerbation of symptoms, or other negative clinical outcomes. Rather, they found that RCTs have consistently demonstrated the effectiveness of SEm in attaining competitive employment, working more hours, and earning better wages than those not receiving SEm. Individual Placement and Support is the most researched of the SEm models and has been shown to produce better competitive employment outcomes than alternative vocational programs, regardless of background demographic, clinical, and employment characteristics.[146] The major components of SEm are (1) competitive employment in the community without extended preparation (contrasted with prolonged preemployment preparation typical of traditional vocational rehabilitation models), (2) integration of employment and mental health services, (3) an emphasis on client preference and choice regarding jobs, and (4) the availability of ongoing job supports. Dixon et al[140] found that outcomes were clearly superior when more components of the model were in place, although they noted that effectiveness of individual model components has not been adequately studied. The one exception to this is integration of mental health and vocational services, which was associated with better outcomes.

In addition, described below are several alternative approaches for improving employment outcomes among individuals with serious mental illnesses, some of which are being disseminated and implemented in community settings. To date, however, little research has evaluated their effectiveness, so this is an area where good comparative effectiveness studies could lead to improvements in a key patient-centered outcome. The Clubhouse Model has shown promise for improving employment outcomes for individuals with serious mental illnesses. While it began as a support system for individuals with serious mental illnesses, some programs have become structurally more like day treatment programs; subsequently, the term is now used to refer to a broad range of programs with varying levels of fidelity to the original Clubhouse Model. The model's early roots as a consumer-led program heavily influence its patient-centered approach to care and services. Members attend Clubhouses voluntarily and determine their level of participation and the type of work activities in which they engage. The goal of the program is to involve members in a community that promotes recovery through relationships and responsibilities within and outside the Clubhouse. In addition to community-based employment and vocational supports, Clubhouses offer a range of services including education, housing, outreach, advocacy, health care assistance, substance-abuse services, and recreational opportunities.[474]

Despite the model's long history and its proliferation in numerous countries, reviews assessing outcomes among members are sparse. A 2010 review produced by the International Center for Clubhouse Development for SAMHSA's National Registry of Evidence-based Programs and Practices[475] examined three outcomes (employment, QOL, and recovery) measured across two studies, only one of which was experimental. That study,[476,477] an RCT comparing SEm outcomes for participants in ACT and Clubhouse, showed that over 2 years, Clubhouse members worked more days and hours per job than ACT participants and earned more wages. Additional analyses including independent and transitional employment outcomes and SEm outcomes over 30 months showed that Clubhouse members worked more weeks and earned a higher hourly wage than ACT participants.[476]

Affirmative businesses, or social firms, are another model with potential to improve employment outcomes for individuals with mental health problems. Developed in Trieste, Italy, in the 1970s, affirmative businesses have gained prominence in Europe and, to a lesser extent, in the United States and other countries. The goals of such businesses are two-fold: to gainfully and meaningfully employ individuals with disabilities in a cooperative work environment and to provide a needed service. For example, after learning that the city had a significant problem with abandoned scooters in a certain area, managers of the Trieste cooperative recognized an opportunity and staffed a scooter-salvaging workshop with disadvantaged youth, many of whom had histories of stealing scooter parts to sell on the streets.[478] Affirmative businesses empower individuals and foster communities and a sense of commitment though a social mission. In a qualitative study of work life among individuals with serious mental illnesses working in a social enterprise, workers reported a sense of belonging and of competence in being a good worker, and that a quality work life meant establishing relationships with coworkers and supervisors.[479] The goals and opportunities supplied by social firms may provide an opportunity for individuals with serious mental illnesses to realize important work-related, patient-centered outcomes. There is insufficient evidence at this time, however, to support this model as a method of improving employment or psychosocial outcomes. Research is needed comparing the effectiveness of these to other employment programs.

Summary and Implications SEm has clear evidence of its effectiveness among individuals with serious mental illnesses. While the Clubhouse and social firms are unique and patient-centered interventions, additional outcome research is needed to support these alternative models of care. Additionally, a metasynthesis of qualitative research on the employment-related views of people with serious mental illnesses[480] found several barriers that, if addressed, might improve outcomes. These include barriers to ongoing support within and beyond the workplace and systems barriers, such as financial disincentives for working and lack of funding for vocational resources.

Individuals Who Are Homeless or at Risk for Homelessness The deinstitutionalization movement has meant reductions in extended hospital stays for individuals with serious mental illnesses. An unintentional consequence of this transition, combined with other economic and housing-related factors, has been inadequate, inconsistent, or unstable housing for many individuals with mental illnesses.[481] Choice in housing is very important to consumers, with many consumers choosing more autonomous living situations when given the opportunity.[481] Piat and Bloom[481] asked consumers and case managers to rank their housing preferences on a list that ranged from one's own apartment to a hospital. The authors found that most consumers preferred living in settings with more autonomy than their current living situations provided. Similarly but to a lesser degree, case managers also favored increased autonomy, preferring housing with both more structure and clinical involvement (eg, supervised apartments).

Housing First and supported housing programs have been developed to address housing needs by providing flexible, need-based services and the supports necessary to place and keep individuals living independently in community-integrated housing. Philosophically, Housing First programs are distinguished from other programs in that they emphasize choice and require neither engagement with the mental health system nor sobriety, to qualify for a permanent residence. Indeed, in at least one study,[482] Housing First decreased homelessness and increased perceived choice and led to decreased psychiatric symptoms, partially mediated by mastery. In contrast, traditional programs typically require abstinence and participation in treatment. Housing First and traditional interventions also differ in that the former focuses on housing stability as a primary policy outcome, while the latter targets addiction through behavioral approaches with the goal of improving clinical outcomes. Kertesz et al[290] contrasted these differences in their review of outcome studies of Housing First and traditional housing interventions for homeless individuals with addiction. They concluded Housing First achieved excellent housing retention, while traditional programs produced reductions in addiction severity but limited long-term housing success. They suggested that future research should compare both types of interventions, in RCTs, with appropriate measures for both types of outcomes, as well as analyses of which programs are optimal for meeting the specific needs and preferences of homeless individuals.

ACT programs also address housing as part of a comprehensive package of mental health and other services. Nelson et al[483] reviewed eight studies that compared ACT to a variety of other models, including ICM, case management, residential housing, and residential treatment (which included case management, treatment for substance abuse, and housing supports). The best outcomes for housing stability were programs that included housing and other support, followed by ACT alone. Compared with standard care, ACT showed improved outcomes for (1) housing stability; (2) reduced hospitalizations and shorter hospital stays (which were offset by increased use of outpatient treatment and social services); (3) higher levels of engagement with treatment and social service staff; (4) client satisfaction with services; (5) some evidence of improved functioning and adaptation to community living; (6) positive self-ratings of overall health and well-being; (7) improved ability to meet basic needs; and (8) improved ability to access material supports from others.[483] Controversy surrounds ACT programs, however. Many are not recovery focused, and their paternalistic approach can be seen as intrusive and coercive.[484]

Rogers[485] conducted a systematic review of various types of supported housing, including those already described here, and found several well-controlled studies of supported housing programs and several studies conducted with less rigorous designs. Overall, the literature suggests that supported housing can improve the living situation of individuals with serious mental illnesses and can help up to about 80% of people to stay in apartments or homes over an extended period. Additionally, the review suggests that although supported housing does not consistently reduce psychiatric symptoms, it can reduce rehospitalization, improve QOL, and increase satisfaction with living situation, *when housing quality is good*. The review found that ICM services generally lead to better housing outcomes, and clinical supports can mitigate isolation if that is a problem. Housing subsidies or vouchers appeared to be helpful in getting and keeping individuals housed, and housing services appeared to be cost-effective and to reduce the costs of other social and clinical services. They also noted that having access to affordable housing *and* having a well-integrated service system is also important to improving housing outcomes.

Individuals in Crisis We can surmise that for many individuals with serious mental illnesses, avoidance of hospitalization—and particularly coercive admission—is a patient-centered outcome. Advanced crisis planning through the use of psychiatric advance directives (PADs), joint crisis plans, and safety plans holds promise for reducing hospitalization and compulsory admissions. PADs are documents created by consumers of mental health services who anticipate a need for future service use and elect to make their preferences for care known in advance. PADs may be executed entirely by the individual, while joint crisis plans involve carers and a third party who mediates negotiation of the plan. Whereas PADs and, to a lesser extent, joint crisis plans are comprehensive in their scope and sometimes include arrangements and provisions outside of psychiatric care (eg, who will care for my pet while I'm in the hospital), safety plans are specifically oriented around keeping an individual safe when suicidal behavior emerges. Henderson et al[486] conducted an RCT comparing use of inpatient services and legal coercion between individuals who created a joint crisis plan for their care and those receiving standard care. They found that the use of an advance plan reduced the number of admissions and significantly reduced use of legally invoked, involuntary treatment. In an earlier pilot study, use of such documents helped the majority of participants feel more involved in their care, more positive about their situation, and more in control of their mental health problem.[487] In addition to these patient-centered outcomes, the collaborative process of creating these documents has potential to increase empowerment and improve therapeutic relationships.

Once individuals enter psychiatric crises, an appropriate and prompt response can minimize further deterioration. Generally, the intent of crisis services is to provide immediate intervention in response to critical incidents in acute phases of illness in order to reduce the risk of relapse and reduce repeat hospitalizations. Murphy and colleagues[488] compared RCTs of crisis intervention models with standard care for people with serious mental illnesses. Crisis intervention appears to reduce hospital readmission, particularly for mobile crisis teams providing in-home response. Further, crisis intervention reduces family burden and is a more satisfactory form of care than hospitalization for both service users and families/carers. At 3 months postcrisis, mental state was superior in those who received crisis intervention to those receiving standard care. Whether crisis intervention is more cost-effective than hospital care remains an area for investigation.

Compared with inpatient hospitalization, residential treatment programs are a less restrictive alternative to acute psychiatric crisis and are characteristically quite different in approach and philosophy of care. While implementation differs, residential treatment programs share common characteristics: fewer residents than typical hospital settings, a caring milieu including intense and regular supportive therapeutic contact, less emphasis on medication, and a less stigmatizing approach to the treatment of psychosis.[489] Still, these care settings are inappropriate for some individuals, including those who are not interested in care, are actively violent to themselves or others, have serious medical needs that would be better met in psychiatric departments in general hospitals, and are actively using substances (though this is not an absolute exclusion in some of these settings). In an overview of residential care alternatives for acutely psychotic individuals, Lichtenberg[489] reported that with regard to clinical and psychosocial outcomes, these models are comparable to inpatient treatment and generally cost less, although research investigating their long-term effects and costs is needed.

While other programs (eg, intensive outpatient treatment) are being implemented as alternatives during crisis, we were unable to find research evaluating their effectiveness. More evaluations of existing crisis intervention protocols and programs are needed. A recently published Cochrane review of crisis intervention for people with severe mental illnesses included only six studies with a total of 984 people.[490] The authors considered the methods of these studies poor (ie, crisis care was poorly defined, samples were not generalizable) and concluded that current crisis intervention efforts may lack sufficient empirical support.

Summary and Implications Alternatives to inpatient hospitalization during crisis show promise for improving clinical and patient-centered outcomes, as well as being cost-effective. Understanding which approaches and characteristics of crisis management produce optimal outcomes may create opportunities to improve crisis management and reduce relapse and rehospitalization.

Individuals at High Risk for Disengagement and Rehospitalization ACT was developed in response to the "revolving door" phenomenon among service users with serious mental illnesses. ACT is a comprehensive set of time-unlimited clinical, rehabilitation, and support (housing, employment, social) services provided directly by a multidisciplinary team in the community setting. Caseloads are low (1:10) and shared among the team, which typically includes a psychiatrist, nurse, case manager, and other professional, paraprofessional, and sometimes peer staff.[491]

ACT has proliferated and become one of the most intensively studied interventions in community mental health.[492] On the basis of its evidence, it is a recommended program for treating individuals who have schizophrenia, are recently homeless, or are at risk of repeated hospitalizations.[140] ACT has been adapted for a variety of populations and has demonstrated improved mental health outcomes (eg, symptom severity, psychiatric hospitalizations)[493,494] and community outcomes (eg, housing stability, educational attainment). It has not been shown to improve outcomes for individuals with co-occurring mental health and substance-abuse disorders.[495]

There is concern and a wide array of opinions regarding whether ACT is coercive and paternalistic. When ACT was developed following deinstitutionalization, client preferences were not central to delivery of care. It was assumed that staff were in the best position to determine what clients needed, and staff values tended to overshadow clients' expressed preferences. Salyers and Tsemberis[484] provide an excellent examination of the philosophical similarities and differences between ACT and the recovery model of care, and outline the challenges of integrating recovery concepts into the ACT model. They point to the need for ACT to align with human rights concepts, the need for providers to shift from "clinician as expert" to a more collaborative and client-centered treatment approach, and the importance of shared values and attitudes in creating a trusting and respectful relationship with clients. The authors list challenges to integrating recovery goals, including mandatory outpatient commitment, lack of client trust in the mental health system's ability to understand and address their needs, constant contact with clients who may not want to engage, medication monitoring among people who may not want to take medications, and the occasional need for providers to act coercively to be effective. Research is needed to adapt ACT programs to make them recovery focused and patient centered.

ICM is sometimes described in the literature as a dilution of ACT, and other times as a heterogeneous group of methods combined to meet an individual's needs.[491] Dieterich et al[496] compared ICM with non-ICM (same characteristics with the exception of larger caseloads) and standard care across 38 trials in the United States, Canada, Europe, and Australia. When ICM was compared with standard care, those in the ICM group were significantly more likely to remain engaged in the service, had improved general functioning, and were more likely to get a job, not be homeless, and have shorter hospital stays (particularly when they previously had longer stays). Results for mental state and QOL were equivocal, and no differences in suicide or all-cause mortality were found. When ICM was compared with non-ICM, those in the ICM group were more likely to be kept in care; however, no other differences emerged. Thus, it is not clear what advantage ICM with limited caseloads confers over non-ICM with maximized caseloads. There were no trials comparing non-ICM with standard care, and such study is warranted.

Summary and Implications ACT and ICM have been widely studied and are effective approaches to improving certain outcomes for clients with serious mental illnesses. Policy makers and providers can target resources more effectively when they have a better understanding of what works for whom, especially for subpopulations, and under what conditions. Importantly, understanding how ACT and ICM components can meet service user preferences without undue coercion is an important task for PCOR. In addition, future research on ACT should focus on examining preferences of clients enrolled in ACT and ICM programs, enhance patient-centered approaches, and identify effects of ACT and other ICM programs on patient-centered outcomes.

Individuals in Need of Daily Living Assistance or Social Skills Training Acute exacerbations of symptoms can compromise self-care skills and functioning. Life skills programs attempt to enhance QOL by providing rehabilitation and training in activities of daily living, including communication training, financial awareness, domestic skills, personal hygiene, and self-care, as well as stress management, medication compliance, forward planning, and transportation. Tungpunkom et al[497] compared different types of rehabilitation therapy (life skills programs, occupational therapy, peer support, and standard care) for individuals with serious mental illnesses. Their review included seven RCTs with a total of 483 participants. The authors concluded that more robust data are needed from studies adequately powered to determine whether life skills training is beneficial for people with serious mental illnesses. They found no significant differences in outcomes between the various types of rehabilitation therapy and standard care.

Similar to life skills training, social skills training is meant to compensate for deficits in skills needed for everyday activities and independent living. Social skills training typically focuses on interpersonal skill development through behavioral instruction, rehearsal, role playing, corrective feedback, and positive reinforcement. Because social skills training has shown significant effects on proximal (skill tests) and distal (community functioning) measures of outcome,[498] it is recommended as a psychosocial treatment (typically part of a bundle of services) for individuals with schizophrenia who demonstrate social skills deficits.

Individuals With Cognitive or Social-Cognitive Deficits Characteristic of many serious mental illnesses are cognitive difficulties, including in areas of attention, memory function, and executive function.[499–502] Social-cognitive abilities may also be affected, including facial affect recognition,[502] social cue perception, Theory of Mind (the ability to attribute mental states to another), and attributional style.[504] These types of cognitive deficits, which are not responsive to pharmacological interventions[504] and in fact may be worsened by them,[505] are strongly associated with low functioning and have been recognized as a rate-limiting barrier to recovery for many.[502] Cognitive interventions aimed at specific[503] and broad-based[506–511] cognitive and social-cognitive deficits have been developed and evaluated in populations with schizophrenia and, to a lesser extent, affective disorders. Collectively, these interventions are termed cognitive remediation (CR). Several meta-analyses and reviews have demonstrated that for individuals with schizophrenia, brief or extended CR produces moderate but statistically significant changes in cognitive functioning, durable over 2 years.[502] Moreover, although CR interventions do not appear to affect clinical symptoms, cognitive improvements resulting from them appear to generalize to long-term personal and social functioning.[502] In the affective literature, the Barcelona Bipolar Disorder Programme has extended CR to include psychoeducation on cognition-related issues, problem solving, and family support with the explicit aim of improving functional outcomes. The modified intervention, functional remediation,[512] has not yet been evaluated, but rigorous investigation is warranted given growing evidence that supports the use of CR for individuals with affective disorders.[506,513,514]

Older Individuals With Serious Mental Illnesses Not unlike many other subgroups described within this report, the mental health and substance-use needs of older adults are complex and frequently unmet by today's health care delivery system. Bartels[515] described the "forgotten territory" in policy advocacy that older adults with serious mental illnesses occupy. These individuals are often left out of efforts to advocate for the elderly more generally and, by virtue of their age, are ignored by those working on behalf of the mentally ill. To date, most clinical and research developments applicable to individuals with serious mental illnesses have focused on adults younger than 65 years, and it is unclear whether findings from those studies generalize to older adults.[516] Our knowledge of appropriate treatments for geriatric mental illness and substance misuse has dramatically increased in the past 25 years, but gaps in understanding remain, and where evidence exists, implementation failure is common.[516] Mental health systems are, thus, ill equipped to address the unique needs of this population.

Barriers to care at the system, organizational, interactional, and individual levels include a shortage of providers trained in geriatric mental health,[517] limited funding or reimbursement for providing developmentally adapted mental health programs and specialty services,[518] ageism and other biases among providers,[515,519] providers' perceptions that certain mental illnesses (eg, depression) are a natural part of aging or an unavoidable symptom of comorbid medical conditions,[520] providers' low likelihood of suspecting substance misuse among the elderly,[519] negative beliefs and stigma surrounding mental illness and substance use, and underutilization of mental health and addictions services and specialists.[517,519] Further, diagnosis and treatment are complicated by developmentally normative cognitive, functional, and sensory impairments associated with aging; comorbid physical illnesses that have impacts on mental health; and medication interactions. These factors converge to result in disproportionately untreated mental illness and substance-use conditions among older adults, with corresponding and significant impacts on health, functioning, QOL, health service use, and costs. With the higher overall standard of living and better treatments for physical and psychiatric disorders, a greater proportion of adults with serious mental illnesses are reaching old age. And with the "baby boom" generation now reaching age 65, the challenges and costs of treating the growing numbers of older adults with serious mental illnesses should be a major focus of patient-centered research and mental health service delivery systems.[517,521]

Areas ripe for CER and PCOR to improve services to this population include (1) identifying older adults with serious mental illnesses in need of services, (2) engaging them in care, (3) determining the most effective interventions (both pharmacological and psychosocial) for this age group, (4) identifying the patient-centered outcomes valued by this group, and (5) determining how to best deliver interventions to achieve optimal patient-centered and clinical outcomes.

We found very few examples of interventions designed to engage older adults with serious mental illnesses, and published trials suffer from suffered from methodological limitations. A systematic review, however, found support for the positive effects of outreach services.[522] This is clearly an area for development. There is also a paucity of comparisons of needs among older and younger persons with serious mental illnesses, and of longitudinal research investigating how needs change over time.[516] Age may be an important moderator of treatment engagement and response. Future PCOR focusing on better understanding of moderators of treatment response may lead to better matching of service users to existing EBPs and to the development of modified or novel interventions.

We found little in the way of evidence-based clinical practice guidelines or treatment algorithms specific to elderly individuals with serious mental illnesses. There is a growing literature, however, showing promising psychosocial interventions that have been adapted or developed and evaluated for use with middle-aged and older adults.[515,516,519,521,523] Bartels and Pratt[521] reviewed psychosocial rehabilitation interventions for older adults with serious mental illnesses and identified several important areas for future CER and PCOR. First, many of the published psychosocial rehabilitation interventions are group based, and there is a need for comparisons of those approaches with individual interventions that target the specific needs and preferences of the consumer. Second, existing and novel interventions need to be compared with regard to their impacts on cognition, depression, social integration, involvement in meaningful activities, and chronic medical illness, as these mutable outcomes are shown to be strongly associated with poorer functioning and lower QOL in older adults with serious mental illnesses.[524] Bartels and Pratt[521] posited a need for intervention strategies that address both physical and mental health needs, integrating health promotion, health care, and illness self-management. To this we would also add preventive health care.

Also highly relevant to PCOR are findings related to the delivery of care, specifically where older adults want to receive care and the correlates associated with institutional care. Adults with serious mental illnesses are more than 1.5 times more likely to be admitted to nursing homes than are Medicaid beneficiaries without mental illness.[525] Mental health treatment in nursing homes is often substandard,[518] and institutionalization is associated with worse health status, decreased availability of family supports, more severe overall symptom ratings, greater cognitive impairment, more severe functional deficits, more problem behaviors, more severe medical problems, and fewer social supports.[521] Given this, it is imperative that the mental health delivery system better understand who is a candidate for institutional care and who might be better served in other settings. Despite popular misconceptions, aging with a serious mental illness is not necessarily associated with a decline in independent functioning or with a need for institution-based long-term care. Aschbrenner and colleagues[526] found that a substantial number of adults with serious mental illnesses in nursing homes may have the functional capacity to reside in less restrictive settings. When the authors examined nursing home admissions and long-stay conversions of younger and older residents with and without serious mental illnesses, they found that, despite a greater proportion of residents being classified as having low care needs compared with residents without serious mental illnesses, those with serious mental illnesses were significantly more likely to become long-term residents. Data showed that 33% of the sample of young residents with serious mental illnesses were classified as having low-care need, while only 8.5% of young residents without serious mental illnesses were classified as having low-care needs. Nevertheless, young residents with serious mental illnesses were 3.9 times more likely to be long-term residents. This same pattern was shown for residents over age 65: 14% of those with serious mental illnesses were classified as having low-care needs compared with 6.6% of those without serious mental illnesses, yet older adults with serious mental illnesses were twice as likely to be long-term residents.

Especially important to PCOR, Bartels[515] found that consumers had strong preferences for in-home or independent living settings. When asked to choose among nursing home, group living setting in the community, or independent supported housing, 40% of nursing home residents with serious mental illnesses believed that a community-based setting would best meet their care preferences and needs. Many individuals, however, are forced into nursing homes because of a lack of affordable community-based residential alternatives. Myopic fiscal policies[518] act against efforts to establish community-integrated mental health services, favoring acute medical care in inpatient settings rather than targeting rehabilitative interventions and support services (eg, Meals on Wheels, senior housing, family interventions that target physical and mental illness management) that improve community living, self-management, social support, and health—key factors associated with successful community tenure.[515]

Our review suggests that in order to best serve older adults with serious mental illnesses, a reorganization of care and service delivery is needed at multiple levels. A necessary prerequisite is the redirection of public funds toward community-based care initiatives and the development of measures to determine who benefits from institutional, community-based, and home-based care models. Also required are the development and evaluation of developmentally appropriate engagement and treatment interventions and support services, as well as evaluation of the implementation of these interventions across various settings.

Individuals Interested in Involving Family and Significant Others in Care Individuals who maintain relationships with relatives and significant others may elect to involve their family members in their mental health care. In a qualitative study of the role of family in supporting recovery, residents of structured community housing identified their families more often than mental health professionals, residential caregivers, or friends as those who most strongly believed in them and their recovery.[527] Dixon et al[140] recommend that when the individual, family, and clinician collaboratively agree that family/carer participation in treatment is acceptable and desired, an intervention lasting at least 6–9 months (or at minimum four sessions) should be offered. Such interventions, often termed *family psychoeducation*, include illness education, emotional support, training in coping skills, and crisis intervention, and have been shown in meta-analyses to significantly reduce rates of relapse and rehospitalization. Dixon et al[140] summarized literature indicating that consumers who receive at least 6 months of family-based psychoeducation show improved treatment adherence, lower perceived stress, and better vocational outcomes than controls. Moreover, their family members reported lower levels of burden and distress and improved family relationships. The benefits of family psychoeducation seem to be even greater for individuals who have had a recent relapse of symptoms.

Individuals With Initial-Onset Psychosis Prevention, early identification, and treatment of psychosis have increasingly been emphasized in mental health programs, especially in the United Kingdom, elsewhere in Europe, and in Australia, although trials are increasingly being done in the United States as well. Early intervention in schizophrenia is defined by early detection and phase-specific treatment using psychological, social, or physical treatments developed and/or modified for use with people at an early stage of the illness.[528] A joint consensus statement of the World Health Organization and the International Early Psychosis Association articulated "universal principles" of early intervention and proposed 10 strategic recommendations that included early identification, primary care treatment, availability of medication and psychosocial treatments, family education and support, and expanded research.[529]

A number of reviews addressing prevention and early intervention have been published in the last 2 years. These reviews, in contrast to earlier ones, have begun to show evidence of some positive outcomes, although the types of interventions vary widely and the evidence is not robust. Preti and Cella[530] reviewed seven RCTs conducted with people identified as at ultrahigh risk of developing psychosis. Interventions ranged from antipsychotic drugs, CBT, combination antipsychotics and CBT, intensive community treatment with family education, and Omega-3 polyunsaturated fatty acid supplements (ethyl EPA). They concluded that the Omega-3 and CBT were effective in reducing transition to psychosis at 12 months. Follow-up after 2–3 years showed that effectiveness was not maintained after withdrawal of treatment, however, and that limited treatment may have delayed but did not prevent psychosis onset.

In a 2010 systematic review and meta-analysis of early intervention services, CBT, and family intervention for people with early psychosis, Bird et al[531] concluded that early intervention reduced hospital admissions, relapse rates, and symptom severity, as well as improved access to and engagement with treatment. Family intervention alone reduced relapse rate and hospital admission rates, whereas CBT alone reduced severity of symptoms but had no impact on relapse or hospitalization. The authors concluded, however, that longer term benefits of the approach and the relative effects of its different components need additional research.

Marshall and Rathbone's 2011 Cochrane Review of 18 RCTs testing early interventions for psychosis[528] found that most studies were underpowered to draw firm conclusions. An analysis of the six studies that investigated a variety of medication and psychosocial interventions to prevent psychosis in those with prodromal symptoms found that neither medication alone nor CBT alone was effective. A combination treatment of risperidone, CBT, and specialized teams was effective, but only for 6 months; at 12-month follow-up, benefits were no longer present.

Authors of this review also reported that studies examining outcomes in first-episode psychosis found few substantial effects on outcomes of suicidality, days in hospital at 1 year, relapse, or treatment compliance. The largest and highest quality study using a specialized team intervention found a few positive findings—better compliance with treatment, fewer individuals leaving the study early, and fewer "not living independently" after 5 years. One study found that vocational rehabilitation resulted in higher levels of employment, and another suggested that family therapy may have small effects. Overall, the authors concluded that early intervention shows some promise but that there are questions as to whether any effects are maintained over long periods. They suggested that larger and more rigorous studies are needed.

Correll et al,[532] in a comprehensive review of early intervention approaches, found a variety of interventions (CBT, antipsychotics, ethyl EPA, and combination CBT/antipsychotics) to have beneficial effects on rates of conversion to psychosis, psychopathology, and functioning compared with control conditions. Consistent with the Cochrane Review, however, effects did not appear to last following termination of the intervention, with the possible exception of the ethyl EPA study previously cited.

An alternative approach to early intervention is the Open Dialogue (OD) model model developed in Finland. This model evolved from a social constructionist framework positing that a person's reality grows out of his or her social context and everyday interactions. The model's origins evolved from the Need-Adapted approach promoted by Alanen.[533] OD[454,455,534] is based on seven core principles: immediate intervention within 24 hours of first contact; a social network perspective that includes the individual, family, neighbors, friends, and, to the extent possible, employers, social service, and vocational agents; flexibility to adapt to the individual's changing needs; staff responsibility for the treatment process; continuity of care; tolerance of uncertainty; and facilitation of communication and promotion of dialogue as a means of understanding the situation.

The OD model has been implemented almost exclusively in Scandinavia (primarily Finland but also Norway). English-language literature on the effectiveness of this model is sparse, consisting almost exclusively of descriptive studies of first-episode cases of nonaffective psychosis presenting in Western Lapland, Finland, between 1992 and 1997. Only one of these[455] included a comparison group treated under a different model. This study compared outcomes of three different populations: service users treated during early development of the OD model, service users treated during the full development period, and a culturally comparable comparison group treated in another area of Finland with a more traditional hospital-based intervention model, including a heavier emphasis on neuroleptic medications. After 2 years, OD service users used fewer neuroleptics at the beginning and throughout treatment and had fewer days of hospitalization than did the comparison group. The OD group also had lower rates of relapse, higher rates of employment, and lower rates of formal disability. Current evidence for this model is insufficient for drawing any conclusions about its effectiveness or the efficacy of the various components of the system intervention, but results are tantalizing. Additional research testing and comparing the model in other cultures, with more rigorous designs, is warranted.

Summary and Implications Early intervention to prevent or mitigate symptoms of psychosis is a highly desirable goal that, if effective over the long term, would bring profound benefits to service users, families, and society by promoting recovery, independence, equity, and self-sufficiency and facilitating the uptake of social, educational, and employment opportunities.[529] Effective interventions also have the potential to dramatically reduce health care costs. At this point, however, no clear intervention has been shown to be effective. Studies are needed to compare the effectiveness of different strategies of early intervention and the relative effectiveness of the different components, separately and in combination. In addition, the value of producing delays in onset should be studied. The ability to complete education and obtain additional work and social experiences prior to onset has the potential to limit disability, reduce social exclusion, and improve long-term outcomes.

Unintended Consequences and External Influences Bosanac et al[535] articulate a number of concerns about the unintended consequences of early intervention to treat psychosis. First, early intervention may divert funding from the most severe forms of psychotic illness even though longer term outcomes are yet to be demonstrated. A second concern is that premature labeling has the potential to disrupt employment, academic, and other opportunities for those so labeled. Third, early use of antipsychotic medications may cause iatrogenic harm, including obesity, hyperlipidemia, diabetes, and sudden cardiac death. Finally, given preferences of young people and their parents for low-intensity community interventions rather than psychiatric mental health services and medication, an emphasis on early treatment may inhibit access and adherence. These considerations should not be ignored.

Patient-Centered Quality Improvement in Mental Health, System and Provider Performance Measures, and Methods of Feedback

Donabedian[536] divided quality improvement strategies into three components: structure, process, and outcomes. Structure addresses the extent to which an organization or system has the requisite structures in place to deliver a service or treatment (eg, trained staff, equipment). Process addresses whether the service or treatment was actually delivered as well as the manner in which it was delivered. Outcomes are measures of response to a treatment or service, whether positive or negative, intended or unintended. In addition to Donabedian's conceptualization, it is worth further characterizing outcomes in terms of their patient centeredness. That is, clinical outcomes may have greater importance to clinicians (eg, symptom control), while other types of outcomes may have greater importance to service users (eg, ability to work or maintain intimate relationships, irrespective of symptoms).[151,153,537] For individuals with such preferences, symptom-related outcomes are less important and thus less patient centered than work- or relationship-related outcomes. To date, a majority of performance measurement and quality improvement initiatives have targeted clinical processes and outcomes deemed clinically important, although some clinical and process outcomes are known to be important to service users (eg, prevention of hospitalization, continuity of care).

Many measures can be applied to assess quality at the level of the individual clinician, facility, or health care system. These measures are crucial in that they often assess factors related to minimum goals or thresholds for acceptable quality in clinical care. Such measures include Healthcare Effectiveness Data and Information Set (HEDIS)[538] measures, as well as the following indicators of service quality specific to individuals with diagnoses of serious mental illnesses:

1. For specialty mental health outpatient services
   a. Continuity of care with the same clinician or team
   b. Availability of evidence-based psychological, psychosocial, rehabilitative, cognitive, and substance-abuse treatments
   c. Availability of family psychoeducation programs
   d. Frequency of medication management visits
   e. Percent of service users with PAD in place
   f. Number of days between request for service and service visits
   g. Availability of crisis management services
   h. Availability of alternative services to hospitalization
   i. Number of days between hospital discharge and outpatient mental health visit
   j. Satisfaction with medications/medication side effects
   k. Routine/regular screening for substance-related problems

2. For inpatient services and other institutional care
   a. Rates of seclusion and restraint
   b. Percent of service users with a discharge plan in place prior to discharge
   c. Availability of medical care
   d. Monitoring of medication-related side effects
   e. Number of inpatients consistent with facility capacity
   f. Provision of evidence-based therapeutic and psychosocial services
3. For service users prescribed psychoactive medications (irrespective of setting)
   a. Percent of service users for whom the dose is within an acceptable range
   b. Percent of service users with contraindicated medication prescriptions
   c. Percent of service users receiving indicated monitoring for medication-related side effects such as weight gain, metabolic problems, blood pressure; agranulocytosis, and tardive dyskinesia.

In contrast to common indicators of service system or provider functioning, many patient-centered measures are most appropriately defined as measures of the usefulness or helpfulness of services provided, from the service user's point of view. To the extent that clinical measures such as symptom control and consumer desire for symptom control are concordant, the clinical measure is also patient centered. Discordance in importance between the value of the indicator to the clinician or system, and the value of that indicator to the service user, presents opportunities for research that (1) assesses the links between clinical outcomes specified as priorities by clinicians and those identified as priorities by consumers, (2) develops indicators that can be routinely used to measure those outcomes service users value the most, and (3) examines relationships between patient-centered outcomes, clinical services, and processes of care.

The long-standing and continuing need to improve the patient centeredness, quality, and appropriateness of services provided to individuals with serious mental illness has been well established.[5,7,9,140,322,518,539–541] We have, therefore, proposed a patient-centered learning system of care—a system that requires feedback and response mechanisms so that changes can be made over time in response to feedback. Some of the extensive literature on quality improvement in health care is relevant to our work here, although a great many quality improvement initiatives in health care focus on organizational and care processes that are not directly patient centered. Nevertheless, relevant lessons have been learned about changing systems of care that have the potential to inform efforts to change the mental health care system—a system with little penetration of quality improvement programs.[541] Thus, we begin with a discussion of health information technology as a building block for quality improvement, then present findings from reviews of various quality improvement approaches and initiatives in health care more generally, followed by a review of their relevance to the mental health system. Finally, to the extent possible, we discuss their application within systems providing care to individuals with serious mental illnesses.

Health Information Technology. Health information technology (HIT) has become one of the key structures underlying quality improvement in health care. Quality improvement and health improvement initiatives rely on HIT for decision support, data extraction, surveillance, process improvements, aggregation, and feedback at the clinician and organizational level, and to assess performance for public and internal reporting.[542] In particular, information from EHRs[542] is crucial to these processes, as are databases that track service use and current and past eligibility for services. The authorization of the Health Information Technology for Economic and Clinical Health (HITECH) Act emphasized the importance of implementing these systems, improving them, and providing common data elements and standards for the exchange of health information.[542] A wide variety of HIT-driven quality-of-care initiatives have been implemented, with mixed but generally positive, modest effects on care quality and efficiency and some improved outcomes.[543–545] The cost-effectiveness of such interventions has yet to be determined, however.[543–545]

Less is known about the value of these systems in behavioral health settings, many of which do not have EHRs in place. Their expected importance, however, is underlined by SAMHSA's HIT implementation program strategic initiative, which is intended to ensure that providers in the behavioral health system—including states, community providers, and peer and prevention specialists—fully participate with the general health care delivery system in the adoption of HIT and interoperable electronic health records.[546] In particular, EHRs are seen as having significant potential for coordinating medical and behavioral health care.[547] More specific to the model of care proposed here, they are an essential component if we are to develop a nationwide learning system that can improve quality of care and patient-centered outcomes in behavioral health.[547]

Summary and Implications The rapid adoption of EHRs and other HITs, and the requirements related to meaningful use of these data and interoperability between systems,[542,544,547] suggest the importance of developing HIT-compatible patient-centered measures for individuals with serious mental illnesses that are meaningful and acceptable to those individuals and their providers. These measures must also be useful as feedback to produce the kind of learning behavioral health care system that is sufficiently responsive to the needs and services required to improve individual outcomes in this group.

Unintended Consequences and External Influences Advances in HIT, HITECH Act requirements, and reforms associated with the ACA are providing incentives to implement EHRs and other HIT systems to track, improve, and coordinate care, although behavioral health providers other than psychiatrists are currently not included in the HITECH initiative. Unintended consequences (despite meaningful use requirements) are most likely to involve lack of interoperability resulting from implementation of a wide variety of EHRs, other systems, and multiple performance measures across a large number of medical and behavioral health providers. To the extent that this happens, data collected will be of limited usefulness at a system level or for research.

Audit and Feedback. Audit and feedback—the process of assessing clinical processes and outcomes and providing the information gathered to clinicians and other care providers—has long been used as a technique to improve quality of care and adherence to treatment guidelines.[548] Reviews of the extant literature on trials of audit and feedback in medical settings suggest that such interventions vary in effectiveness, but the wide range of multifaceted feedback mechanisms make it difficult to determine whether audit and feedback improves clinical outcomes generally and which approaches to feedback are effective and which are not.[549] Audit and feedback assessment may be applied at any level in the system—structure, process, or outcomes. The information can be used at the individual level as an indicator of response to services or treatment, or it can be aggregated at the clinician, organization, or system level.

Effects of audit and feedback in medical settings are generally small to moderate in size, with larger effects associated with lower levels of concordance with guidelines at baseline.[550] Some evidence suggests that audit and feedback is more effective at improving clinical processes than clinical outcomes.[549] It appears as well that characteristics of the feedback factor into its effectiveness. That is, the most effective feedback is frequent, timely, credible, nonpunitive, and delivered both verbally and in writing; contains specific suggestions for improvement; is delivered by a supervisor or senior colleague; and contains measurable targets and an action plan.[548,550,551]

Most of the research on audit and feedback has been carried out in medical settings. A 2003 Cochrane Collaboration review of outcome measures and needs assessment tools for schizophrenia and related disorders[552] found no publications that met criteria for review, suggesting the limits of the literature in this population. A more recent meta-analysis of audit and feedback in a few mental health settings suggests modest positive short-term effects similar to those found in medical settings, but no lasting effects on outcomes.[553] Most of the service users included in this meta-analysis were women (two-thirds), and most had affective disorders, although two studies included individuals with schizophrenia. Conclusions are, thus, limited in their application to individuals with serious mental illnesses. The included studies used a wide range of outcome assessments, including symptom measures (almost universal), needs assessments, treatment satisfaction, life satisfaction, social support, social and interpersonal functioning, and measures of working alliance. Despite the wide range of outcome measures collected, the usefulness of particular measures for informing and improving clinical processes and outcomes remains unknown.

A more promising feedback approach for improving care and outcomes among individuals with mental illnesses, particularly serious mental illnesses, measures service user and clinician assessments of a wide range of domains (eg, unmet needs, global well-being, symptoms, general functioning, housing, relationships, finances, psychological distress, and sexuality) and then uses these assessments, and their differences, to foster communication and treatment planning, and to reduce discordance in perspectives between clinicians and consumers.[343] A recent review of such approaches suggests that both clinicians and consumers find the feedback useful, that it reduces discordance in clinician-consumer assessments, that outcomes can be improved, and that such feedback can be cost-effective.[343]

Summary and Implications There is a need to develop patient-centered outcome measures that are both meaningful to individuals with mental illnesses and, when provided as indicators of care quality to clinicians and systems, useful for informing care processes and practices. In addition, we need to know the necessary characteristics of audit and feedback procedures, including key components of facilitated clinician–consumer discussions. We also need to better understand the kind of content needed to make feedback useful for informing stakeholders at the system, clinical, and service user levels. We find promise in approaches that provide concurrent feedback to providers and service users, with prescriptions for discussions regarding feedback, reducing discordance, and increasing collaboration.

Pay for Performance. For more than a decade, P4P has been used widely in efforts to improve health care quality, with programs implemented within a broad range of payment arrangements and service settings, including the British National Health Service, Medicaid, and a host of private health plans and hospitals. Despite its widespread use, evidence to date suggests large variation in the effects of P4P on quality-of-care outcomes.[554–558] It has been used to try to improve quality of care at many levels, including for individual providers, at the team and organization level (including hospital performance), and at the health plan level.

To date, reviews of P4P programs in general health care settings suggest that it is more likely to yield improvements in process targets than in outcomes targets.[554] In addition, there is no evidence to date of positive effects of P4P on outcomes measuring patient centeredness, but there is evidence that stakeholder involvement in selecting and defining targets for improvements produces larger effect sizes.[554] P4P appears to be most effective when there is greater room for improvement from the beginning, when it is focused on process and intermediate outcomes (eg, cholesterol screening, vaccination) rather than individual-level outcomes, when stakeholders are involved in setting targets and goals, when the program is communicated clearly and directly to those responsible for making changes, and when the P4P target, goals, and methods are adapted to the local context.[554] A recent large-scale evaluation of long-term patient outcomes in the Medicare Premier Hospital Quality Incentive Demonstration, however, found that the P4P program did not improve mortality outcomes, as had been expected.[559] This evaluation included more than 6 million patients treated for acute myocardial infarction, congestive heart failure, or pneumonia, or who underwent coronary artery bypass grafting.

Applications of P4P in behavioral health settings have been limited, and questions have been raised about whether or not P4P is an appropriate tool when tied to clinical behavioral health outcomes.[560,561] Of particular note are findings that P4P is most effective in general health care settings when used to improve process outcomes with clear, simple targets (eg, preventive screenings, vaccination rates), rather than clinical outcomes, especially among complex patients. These findings suggest that at minimum, targeted outcomes need to be carefully chosen to improve success. For example, Liptzin[561] argued that while standardization of measures is necessary if we are to make comparisons across clinicians and organizations, general behavioral health measures are neither sensitive nor specific enough to reliably measure treatment outcomes for disorders as varied as those encountered in behavioral health settings (eg, depression, schizophrenia, PTSD).

Thus, for P4P and other behavioral health quality improvement programs, it is a significant challenge to find measures that are useful and valid for measuring outcomes, that can be agreed upon by relevant stakeholders, and that can be used across payers in order to reduce complexity at the clinical level.[561] In addition, if comparisons across clinicians and organizations—and corresponding compensation—are to be fairly distributed, risk adjustment for differences in case complexity (eg, severity of the primary mental health problem, comorbid conditions) is a prerequisite. However, risk-adjustment systems in mental health remain poor.[561,562] Finally, there must be mechanisms in place for collecting, analyzing, summarizing, and then providing data to participating providers and organizations, and the quality of these data must be trustworthy to be seen as useful to clinicians.[561]

In a recent review of P4P in behavioral health, the authors report results consistent with Liptzin's[561] concerns. In particular, the most common obstacle to P4P implementation was lack of practical, valid outcome measures for disorders other than depression (for which the Patient Health Questionnaire-9 [PHQ-9][563] was considered acceptable by a range of stakeholders).[564] Measures used to determine pay were consistently process based, even among those programs that included the PHQ-9 in their measurement package.[564] Interestingly, a new study provides support for conclusions that a focus on process targets, using disorder-appropriate outcome measures, has potential for improving behavioral health outcomes. Unützer et al[565] studied a P4P program for adults with depression in primary care that focused on process targets and used the PHQ-9 as an outcome measure. This program provided training to clinicians in managing depression and regular audit and feedback using a well-established approach to facilitate care integration. Results of the program were positive, with patients in the P4P programs significantly more likely to show a reduction of 50% on the PHQ-9, or to obtain a score of less than 10 (indicating absence of depression) on the measure, than those not in the P4P programs. Patients in the P4P program were also more likely to achieve these outcomes faster than others. Depression treated in primary care represents a less complex condition than the serious mental illnesses addressed in this report, but these results suggest the value of stakeholder-acceptable measures when targeting outcomes improvement.

Summary and Implications Little is known about the applicability of P4P in behavioral health settings. To evaluate the effectiveness of programs for individuals with serious mental illnesses, there is a need for commonly acceptable process measures that are linked to outcomes for different disorders, as well as appropriate disorder-specific, patient-centered outcome measures (in addition to common clinical outcome measures). More importantly, if P4P is to be considered fair when implemented in mental health settings, good methods for risk adjustment are essential.

Unintended Consequences and External Influences If process and outcome measures are used to determine compensation in P4P programs, and risk adjustment methods for dealing with differences in complexities of caseloads are poor, then providers and organizations that provide services to those with the greatest and most complex needs may be unfairly penalized. This can also lead to unwillingness to provide care to such individuals, reducing access to care for the most vulnerable. An additional problem with unintended consequences is related to service users who refuse or are unable to complete outcomes assessments, causing resentment among physicians whose performance assessment may be affected. This may also lead physicians to disenroll noncompliant service users.[566] These problems may present more frequently among service users with serious mental illnesses, given the complexity of their mental health conditions combined with oft-comorbid medical and addiction problems and problems engaging some individuals in services.

Publishing Performance Data. Another mechanism used to promote quality improvement in health care in recent years has been public reporting of patient care performance data. Reporting has been carried out at several levels, including for health plans, hospitals, and providers. Most studies of the effects of these efforts have focused on mortality or cardiac procedures, although some recent studies have examined the effects of reporting on consumer selection of health plans and providers.[567]

Evidence for the effectiveness of public reporting is mixed, and its usefulness has been questioned as a tool for improving patient safety or increasing patient centeredness.[567,568] In general, some evidence suggests that publishing performance data can spur quality improvement efforts and improve some outcomes, but conclusions are limited because most evaluations have focused on a small number of studies, many of which examined the same reporting systems.[567]

While no evidence has been found for influences of reporting on consumer selection of hospitals, publishing quality information about health plans may affect consumers' selection when they are aware of the information and can recall it.[568] Quality information may also produce some switching from lower performing to higher performing health plans.[567]

Beyond the HEDIS behavioral health measures targeting depression care and posthospitalization follow-up for mental health hospitalizations, we are unaware of other publicly reported behavioral health measures. This is likely a result of the same difficulties of measurement and risk adjustment that are detailed in the Pay for Performance section. Interestingly, an Australian mandate for public reporting of quality outcomes in behavioral health may spur new methods designed to address these measurement problems.[560] In addition, because a large proportion of mental health care is provided in publicly funded settings, it is not clear whether the market model that underlies this approach has any applicability.

Unintended Consequences and External Influences There is evidence for a variety of unintended consequences related to public reporting of quality data. Individuals in neighborhoods with lower socioeconomic status may have increased access to care, because public reporting attenuates access disparities, but they may also be more likely to receive care from poorer performing providers. Meanwhile, individuals living in higher socioeconomic neighborhoods are more likely to receive care from higher performing providers.[567] In addition, publishing performance data has led poorer performing hospitals to stop reporting quality data, led poorer performing providers to stop providing care, and led to an unwillingness to care for high-risk, complicated patients.[567]

Almost no information exists about the process or effects of publishing performance data in behavioral health for individuals with serious mental illness. Problems inherent in measurement of these data, and in risk adjustment for complex or high-risk patients, suggest that developing methods for fair assessments and publication of such data will be difficult without negatively affecting access to high-quality care for patients in the greatest need.

Implementing Patient-Centered EBPs and Clinical Guidelines Quality improvement initiatives that have been applied in mental health settings have generally involved implementation of evidence-based clinical guidelines or evidence-based treatments and interventions, ranging from medication guidelines[569,570] to guidelines for psychosocial treatments (cf. Lehman).[322] Interestingly, many of the psychosocial EBPs—such as SEm, supported housing, and social skills training—have been designed to target outcomes that are patient centered. Yet, it is these programs that have encountered the greatest barriers to broad-based adoption.

Implementation research studies suggest that evidence-based approaches, like many other efforts to improve care quality, have produced mixed results. Generally, greater improvements are found in structure and processes of care than in patient outcomes.[571] In fact, a review of implementation of psychiatric guidelines suggests few effects in mental health care; the authors found that most effects on performance and outcome were modest at best and temporary.[572] In addition, guidelines have tended to be narrowly focused and thus less useful for more complex patients, particularly those with comorbid conditions.[573]

In response to failures to adopt EBPs or to disseminate and implement clinical guidelines effectively, implementation science has increasingly focused on (1) how to move evidence-based scientific findings into real-world practice settings while maintaining reasonable fidelity, (2) identifying and overcoming the barriers to adoption and implementation, and (3) fostering those factors that are facilitators of these processes. This field is still in its infancy, but some consistency in findings is emerging. First, effective implementation of EBPs requires a complex process that involves organizational leaders and policy makers who take the initiative to fund the program, involve and support staff members, and provide for other costs during implementation.[574,575] This requires that policy makers and administrators be given information about the value and effectiveness of EBPs and that they are shown the links between consumer preferences and EBP outcomes.[574,575] Also, clinicians need help and support to communicate with consumers about EBP recommendations and to address their concerns.[574,575] Information is now available about approaches that do not work. For example, neither training nor information alone is effective for promoting implementation of EBPs.[574] Similarly, organization-based (program- or practice-centered) approaches are more effective than provider-based approaches, because EBPs that reside only within a provider can be lost when he or she leaves an organization.[574,576] Finally, in the context of organizationally driven implementation, individual performance feedback and coaching show the best improvement in improving acquisition of new clinical skills.[577]

A wide variety of EBPs have been developed targeting outcomes for individuals with serious mental illnesses. Learning which of these EBPs are most highly valued by service users in differing circumstances would be useful.

Process Improvement. Various models of process improvement have been derived from engineering, industry, and other fields and adapted to health care. These include the Institute for Healthcare Improvement's rapid-cycle process-improvement efforts using Plan-Do-Study-Act cycles with learning collaboratives to teach process-improvement techniques, Total Quality Management, Continuous Quality Improvement, Business Process Reengineering, lean thinking, and Six Sigma.[578] These models, despite their differences, share many common characteristics. A recent review of their effects in health care systems suggests that they produce mostly modest effects when certain necessary, but not sufficient, conditions are met.[578] In particular, a recent comprehensive review of process-improvement strategies commissioned by the Scottish National Health Service found that the success of process-improvement efforts depends on the following conditions: provision of the practical and human resources to enable quality improvement; active engagement of health professionals, particularly doctors; sustained managerial focus and attention on the process-improvement effort; use of multifaceted interventions; coordinated action at all levels of the health care system; significant investment in training and development; and the availability of robust and timely data through supported information technology systems. Improvement efforts were most likely to succeed when these conditions were met *and* when those responsible for implementation recognized the generic characteristics of health care organizations that make quality improvement challenging; carefully considered and then adapted the interventions to local circumstances; involved individuals at all levels of the organization, from front-line clinicians to senior managers; and aligned process improvements with existing resources and strategy objectives.[578]

Summary and Implications Health care policy related to quality improvement in the United States is increasingly based on linear models that assume that competition, informed consumers, and a market model will be the most effective methods for improving quality of care and accountability. The at-best modest effects seen across such market-driven models suggest that it may be time to develop alternative models for improving quality of care. Such innovative models may be particularly important in the context of behavioral health, and especially for more serious conditions, because quality improvement efforts appear to be less effective for individuals with more complex problems.

Key barriers to implementation of process improvements in the mental health system include lack of HIT infrastructure, limited staff resources, and lack of widely agreed-upon process measures. In addition, the links between existing process measures and patient-centered outcomes are unclear. There is a need to identify new ways to effectively implement quality improvement initiatives, including process improvements, in public health and mental health settings, and to link those improvements to patient-centered outcomes.[541,579]

Feedback Systems and Methods for a Learning System

Despite calls for significant changes from the Surgeon General,[540] the President's Commission,[5] the IOM,[7] and the Schizophrenia Patient Outcomes Research Team,[322] the last two decades of health care reform and quality improvement efforts have produced, at best, slight to modest improvements in outcomes for individuals with serious mental illnesses.[541] In the previous sections, we have reviewed approaches and methods used in efforts to improve the quality of health care and patient outcomes in medical and mental health settings, concluding that these methods have disappointingly limited effects on individual-level outcomes even when they promote better care processes and increase efficiency. They suggest that we have adopted less-than-effective approaches to improving health care outcomes.

Given the limited success of past efforts, it is critical that we take advantage of new opportunities to reconsider how we approach care, services, and outcomes improvement for people with serious mental illnesses. Such opportunities are emerging from new and developing HITs, changes required by the ACA, the increased interest in and focus on recovery and patient-centered outcomes, and efforts to reorganize care for patients with complex conditions.

Complexity science provides an alternative approach to the linear methods suggested by many quality improvement, performance measurement, and feedback models. This approach defines care systems as complex adaptive systems with fuzzy boundaries and active agents ranging from service users and family members to medical, office, and information technology staff, to clinicians and administrators. These systems continually self-organize and, as they interact with each other and the environment in which they exist, allow new behaviors to emerge. The systems adapt based on information flow, interaction, and exchange among stakeholder agents through a process of learning and sense-making—a process that shapes the systems' responses to information and subsequent interactions. Indeed, information by itself is not expected to produce change without an associated process of interaction and exchange among system agents and agents in the environment.

This approach is consistent with findings from our reviews that point to the importance of facilitating interactions *within* organizations and interactions *between* service users and providers. For example, (1) continuity of care with the same clinician over time fosters relationships that support recovery from serious mental illness;[52] (2) the most effective audit and feedback programs encourage discussion between service users and providers about the feedback[343] and provide frequent, timely, nonpunitive, written feedback with specific suggestions for improvement[548,551]; and (3) the most effective P4P systems involve stakeholders in selecting and defining targets for improvements, include clear and direct communication to those responsible for making changes, and adapt P4P targets, goals, and methods to the local context.[554]

Such approaches are much more consistent with those suggested by complexity science than are the more common approaches to performance enhancement and quality improvement reviewed here. That is, they are consistent with a focus on how organizational culture and climate can promote learning and adaptation among systems, and how promoting positive organizations characterized by positive interactions and teamwork—organizations where individuals and groups flourish—can lead to improved performance. There is a large and varied literature on these topics,[580–595] only some of which has been tapped by health care and mental health services researchers.

The current system's inability to substantially improve individual outcomes in the face of significant efforts, information, and investment suggests that our understanding of the ways in which the current system affects outcomes is not accurately specified. We propose that an alternative, nonpunitive, learning- and interaction-based focus is necessary to improve quality of care, rather than additional efforts to incrementally improve outcomes through implementation of EBPs or development of slightly better performance measures. Consistent with Berwick's recommendation for the health care system as a whole,[596] we suggest that it is time for a radical paradigm shift—one that is focused on interaction-based approaches such as team-based care and patient-centered medical and mental health homes. Most important, we propose an approach that facilitates learning through interactions among all the stakeholders in the system. As Berwick has said, "the interaction is not the price of care; it is care itself" (p. 51). Through such interactions the system itself has the opportunity to become a learning system.

The differences between an interaction-based, patient-centered approach and the care processes characteristic of the current system are substantial. In adopting a patient-centered approach to this report, our team was confronted time and again with the profound disconnect between the care and services offered by the current system; the outcomes used to assess the effects of care provided; the structures, processes, and service packages targeted to improve care; and the needs, wishes, and desires of the people who receive services. As such, the current system knows neither *how* to routinely measure or aggregate patient-centered outcomes nor *what* most of those outcomes should be. Thus, it is not surprising that changes to the system have had limited effects on service user outcomes. Without information about what the outcomes should be, the system cannot adapt to address those outcomes. Moreover, key research questions are intertwined with availability of the right measures for assessing outcomes. If our measures are not valid, then it follows that our answers are incomplete at best.

Early on, as we worked with technical experts and stakeholders, we identified two key research questions that help illustrate this point. First, how do we best involve customers in the design of the care they receive? And second, how do we involve customers in the choices, development, and selection of outcomes? After reviewing the literature on stakeholder preferences, however, we came to realize that we already knew how to involve customers in care design, care development, and outcomes selection.[343,597–600] We then adopted an alternative perspective, which resulted in a set of reformulated questions that were quite different in tenor from the first set. For example, we realized we might more appropriately ask:

- What are the *barriers* to involving customers in the design of the care they receive and how can these barriers be overcome?
- What is *preventing* the system from involving customers in the choices, development, and selection of the outcomes that apply to them, and how can this be remedied?
- What are the outcomes *preferred* by people with serious mental illnesses, and what are acceptable methods for measuring those outcomes?

Once we have clear answers to these patient-centered questions, we can move to the next stage of the process: identifying measures that can be used to evaluate progress over time for service users, and those that can be aggregated to provide performance feedback to clinicians, teams, organizations, the care system as a whole, and the community providing financial and other support for care. In a learning, complex adaptive care system, it will be this information, and the interaction and response from stakeholders, that drives the adaptation needed to improve patient-centered outcomes. Various measure-related key questions for CER and PCOR flow easily from this point. Such questions, some of which are listed in supplementary appendix C, can be identified at all levels specified in the analytic framework (see figure 6), working backwards in the model from individual-level outcomes. (The original list of all questions generated in a face-to-face project meeting with our stakeholders and technical experts appears in supplementary appendix B.

It is important to point out, however, that we are still in need of a good theoretical model and corresponding understanding of how to strengthen the processes that produce the positive interactions that lead to adaptation, responsiveness, flexibility, and improved outcomes. We have observed effective systems but do not yet truly understand how they produce the outcomes they do.[601,602] For example, we do not know how to foster the balanced, healthy relationships and interdependencies that produce trust and that can be used to internalize and process information to enable system-level adaptation. Models and measures of these processes, in addition to clinical processes, are needed.

Fortunately, a great deal of useful research has already been conducted on different structural approaches, care processes and their characteristics, and different service packages (see Care and Service Delivery Models and Structures section). Furthermore, a substantial body of recent research has addressed consumer and stakeholder preferences, needs, and desires (see Stakeholder Perspectives section). This information on preferences needs to be converted to existing outcome measures and used to inform adaptation of these measures.

In addition, a large number of existing measures could be evaluated for their acceptability and importance as patient-centered measures. Many of these measures are reviewed in Hermann's compendium on measurement-based quality improvement in mental health, and his consensus work with stakeholders is an important step forward.[603,604] Other useful resources for measures that might be assessed or evaluated for patient centeredness include the Center for Quality Assessment and Improvement in Mental Health (http://www.cqaimh.org/); structural, process, and outcome measures suggested by Pincus et al[541]; structural measures by Watkins et al[605]; the Health of the Nation Outcomes Scales[606]; the Australian National Mental Health Performance Indicators and Outcomes Measures[607]; measures of patient-centeredness in inpatient settings by Groene et al[608]; structural, process, and outcome measures for people with serious mental illnesses and co-occurring medical or addiction problems suggested by Kilbourne et al[609]; and, for patient-centered outcomes, both NIH's Patient Reported Outcomes Measurement Information System (http://www.nihpromis.org/) and the extensive report from the Bamford Implementation Rapid Review Scheme: Patient Outcomes for Measures of Recovery and Capturing Feedback from Patients in Order to Improve Service Improvement.[343]

Patient-Centered Outcomes

> Routine assessment of patient-reported outcomes…might reduce potential discrepancy between patients and professionals, and improve outcome, although there is little empirical evidence to support this assumption at present…For the future development of patient-reported outcomes, the most pressing issues are conceptual clarity and the consideration of empirical findings, particularly the association with other outcomes.[608(p25)]

Existing Scales and Measurement Techniques There is an ongoing need for conceptual models organizing the perspectives of different stakeholders, as well as an array of valid and reliable measures that are adequately patient centered, consumer informed, and sensitive to change. Progress is being made, however,[291] particularly in the area of recovery measures.[343] In the sections that follow, we briefly review outcome domains that have been identified as relevant to stakeholders, and we suggest opportunities for researchers in each of these domains.

Recovery Measures Donnelly et al[343] conducted an extensive review of measures assessing recovery among service users and recovery orientation among providers. Two key questions guided their review: What are the costs and benefits of using these measures? What is the relationship between outcomes related to personal recovery, and those related to clinical recovery? The authors used an integrated, multilevel approach to measurement, feedback, and system transformation, originally developed as part of the British Mental Health Outcomes Measurement Initiative (see figure 9). (Fonagy, P., Matthews, R., Pilling, S. The Mental Health Outcome Measurement Initiative: Best practice guidance for local implementation. Adapted from the report from the Chair of the Outcomes Reference Group. Leeds, UK: National Institute of Mental Health in England; 2005.) We believe this type of approach will be central to developing the type of learning system of care we have proposed.

Nevertheless, there are advantages and disadvantages to assessing and conceptualizing recovery and outcomes as distinct constructs. These are clearly overlapping and intersecting domains, but recovery cannot and should not be attributed solely or even largely to mental health services, unless the causal factors and pathways are identified. Recovery should be understood as more than an outcome of treatment, conceptually and empirically, because it is based on a complex array of factors, including learning, adaptation, and experience.[337] In this light, we must consider increasing challenges for measurement in general, and recovery in particular, that arise from the conceptual bases defining what is being measured, the needs and interests of the measure developers, and the intended uses of the findings. The central issues concern insufficient inclusion of subjective and experiential data, whether the factors or domains assessed are as important

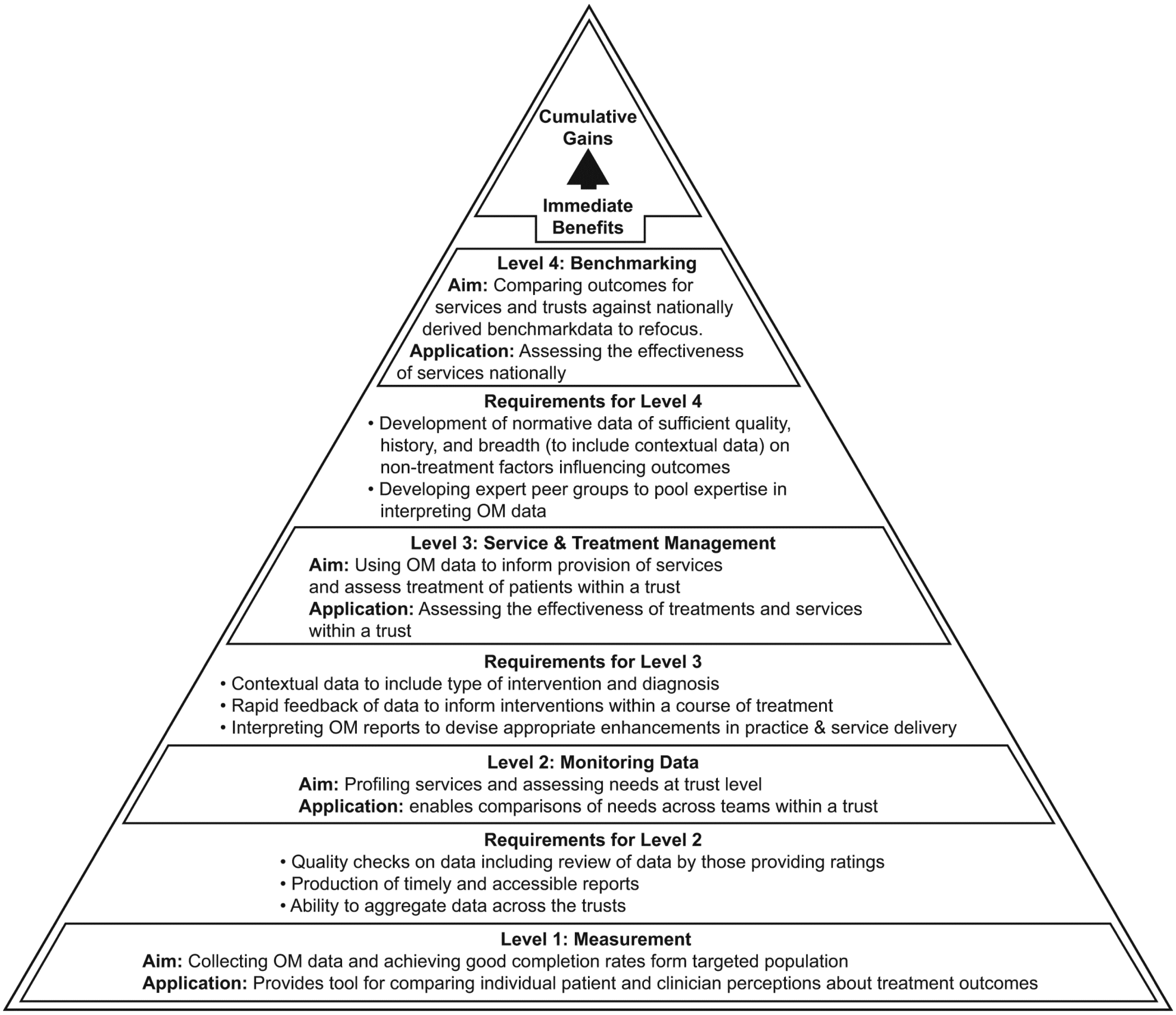


Fig. 9. The benefit pyramid from the British Mental Health Outcome Measurement Initiative[337] (used with permission).

to service users as they are to other stakeholders, and the best methods for eliciting information and conducting analyses.[161] Researchers who identify themselves as mental health consumers are growing in influence and number, and their involvement in many areas of mental health outcomes assessment will be central to improving the validity and utility of recovery measures and trajectories.[611] Several measures of recovery and engagement in services have been developed with consumer input and direction, but we are not aware of recovery measures developed by consumers that are in widespread use in evaluation and outcomes research. The recovery STAR tool kit[612] and Refocus recovery manual[613] are examples of current consumer-developed recovery practices and indices.

The move by many clinicians and organizations to a recovery-oriented model of care has also led to some new outcome measures.[159] These include measures assessing resilience, empowerment, self-esteem, sense of coherence, hope, and recovery. In their early review, McCabe et al[610] concluded that self-reported outcomes varied in their conceptual and empirical foundations but that most targeted satisfaction with treatment. The more recent review by Donnelly et al,[343] however, identified a large number of recovery and recovery-related measures. These measures range from individual-level measures of recovery to system measures assessing the recovery orientation of services. The review team identified several measures across assessment domains that met quality criteria. These included the Recovery Assessment Scale,[614] the Recovery Enhancing Environment Measure,[615] the Recovery Oriented Systems Measure,[616] the Recovery Interventions Questionnaire,[617] the Recovery-Oriented Practices Index,[618] the Recovery Promotion Fidelity Scale,[619] and Recovery Self Assessment.[620]

Some of the more recent measures diverge from more traditional measures in both their development (more likely to involve service users' perspectives) and their topics. For example, Castelein et al[621] compared three empowerment scales across a population of people with psychotic disorders in the Netherlands: the Empowerment Scale, the Personal Empowerment Scale, and the Mental Health Confidence Scale. The authors concluded that each instrument assessed some level of empowerment among persons with serious mental illnesses but noted that the definition of *empowerment* was too broad to have convergent validity. The Mental Health Confidence Scale was recommended due to its good psychometric qualities combined with its clinical usefulness.

Oades et al[175] also sought to develop a scale that would measure mental health service provision using consumer input and a consumer-directed evaluation framework. Eleven themes were assessed, yielding two factors, which the researchers named *empowerment* and *dehumanization*. The measure was found to have satisfactory internal consistency and appeared useful with inpatients and outpatients. Further research is needed to establish test–retest reliability and criterion validity.

Hope Measures Measures related to hope are largely found in the literature on recovery.[158,291,343,613,622–625] For example, Donnelly et al[342] considered hope to be a central domain of the recovery process, along with connectedness, identity, meaning in life, and empowerment. Leamy et al[613] also created a conceptual framework of recovery that included hope and optimism as one of five critical processes of recovery. Donnelly et al[343] reviewed a total of seven specific items for hope and optimism in three instruments: the Recovery Self-Assessment (RSA), which contained two items; the Recovery Enhancement Environment measure, which included three items; and the Recovery Oriented System Instrument, which contained two items. Psychometric properties for these instruments were reported as being solid. The authors also noted that among the five recovery domains, hope and optimism were the least covered in the assessment tools and that more research is needed in this area. Similarly, hope is included as a primary process in the Stages of Recovery Instrument as developed and reported by Andresen et al.[291]

A 2008 systematic review[626] evaluated measures of hope used in psychiatry and identified 49 definitions and 32 instruments. The authors determined that the concept of hope encompasses seven different attributes or characteristics, including a time component, future orientation, the service user's goals, the service user's sense of personal control, environment and other circumstances, spirituality, and personal characteristics. Eleven studies used hope as a predictive variable for individual outcomes, but results were not conclusive. The authors argued that few hope instruments have been used in the mental health field and suggested that empirical evidence on the value of hope as a predictor of positive outcomes is lacking.

Schrank et al[626] conducted a systematic review to evaluate the evidence related to hope scales used in mental health research, including the determinants of hope, self-management strategies that promote hope, and interventions to increase hope. The review included 57 studies, 49 of which were quantitative, with the rest being qualitative. Scales assessed included the Snyder Hope Scale, the Herth Hope Scale, the Miller Hope Scale, items from the Recovery Assessment Scale, the Zimmerman Hope Scale, and three other scales used in only one study each. All scales included attributes of personal control and personal characteristics, and most scales included most of the conceptual domains of hope outlined in the 2008 review (see above). The authors concluded that there is sufficient consistency across the instruments to allow comparison of determinants, self-management strategies, and interventions, but they note that in some cases, comparing the scales may not produce accurate results as different scales measure different aspects of hope.

In other studies, Siu et al[622] examined the validity of a new instrument to assess perceived importance of a number of elements in the recovery process, including hope. Using a sample of 101 psychiatric inpatients (primarily women with diagnoses of schizophrenia) in Hong Kong, the study found that hope was rated important by 86% of the study participants, and that the measure had high internal consistency. Yanos et al[625] used the Beck Hopeless Scale to examine negative outcomes resulting from internalized stigma, finding that such outcomes were mediated, in part, by hope.

As with other measures in the recovery domain, more information is needed about consumer perspectives related to the different dimensions included in the concept we call "hope," whether the dimensions of hope are valued outcomes, and, if so, how best to measure them. Once these outcomes are measured, we need to know the ways that hope can be affected by mental health care and other services.

QOL Measures QOL measures have a long history in assessments of subjective well-being among individuals with diagnoses of serious mental illnesses. Most of these measures have been developed specifically for this population, querying respondents about multiple life domains that range from housing to social relationships. Many researchers consider these measures to be patient centered, although most measures have been developed by researchers and clinicians without the involvement of service users. Nevertheless, a distinct advantage of these measures is that they have been used as measures of treatment outcomes across a wide variety of interventions and have thus been linked to various service programs and packages. These include CCMs,[361,369] integrated care models,[297] supported housing programs,[485] approaches to improving relationships with providers,[52] use of a recovery orientation that addresses families' needs and preferences,[147] and efforts to reduce coercion.[79]

Several comprehensive reviews of these measures are available,[627–632] but little is known about how well they represent consumer preferences or values. Shrivastava et al[633] suggest that differences found in outcomes when surveying service users, relatives, and providers likely result from limitations in the measures themselves.[291] The fact that these measures can be used to identify response to services suggests that they may provide an important body of work that, if evaluated and reconfigured to reflect the preferences of service users and their families, could provide good indicators of patient-centered, service-related outcomes.

Needs Assessments Assessing the needs of consumers is foundational to their engagement in services and the creation of patient-centered service packages. In busy public mental health systems, standardized checklists and templates are commonplace and are often shaped by administrative and fiscal requirements for information, rather than consumer preferences. As a result, the categories and descriptions of personal, social, and clinical characteristics are predetermined.

While it is widely recognized that assessment of needs must be an ongoing process that is linked to outcome evaluation, few instruments are available, despite their critical importance in a patient-centered service system. The Camberwell Assessment of Need (CAN),[634–636] developed in the mid-1990s, is the most widely used needs assessment instrument for people with serious mental illnesses. The CAN has several versions, including some recent adaptations that give the instrument value in broader applications. Twenty-two areas are evaluated, including accommodation, food, self-care, looking after the home, daytime activities, physical health, psychotic symptoms, information about condition and treatment, psychological distress, safety to self and others, alcohol, abuse of drugs, company, intimate relationships, sexual expression, child care, access to a telephone, education, transport, budgeting, and benefits.

The original CAN relies upon self-report of the service user to clinician and then requires the clinician to make a rating of need. The developers noted that service users and staff identified a similar number of needs, but in different areas. There was most agreement in those areas where services were already in place, such as housing or employment.[635] Recently, Trauer et al[636] developed and piloted a more direct consumer-report version of the instrument called the CANSAS-P, adding, for the first time, the response option "I do not want to answer this question." Interestingly, it appears that unwillingness to discuss a need in the previous version resulted in ratings of "no need." This adaptation of the CAN holds promise for patient-centered needs assessment, shows the importance of understanding consumer perspectives when assessing needs, and provides a way to identify domains that may need to be addressed in other ways.

Another instrument, the Adult Strengths and Needs Assessment (ANSA),[637] is an open-source, manualized tool designed to support decision-making regarding service planning, levels of care, quality improvement initiatives, and outcome measurement. The ANSA covers eight major domains, using a 0–3 scale for strengths and needs, but it begins with "My Life, My Story"—an open-ended discussion that sets the framework for the questions that follow. It can be adapted to the specific needs of local service systems.

Summary and Implications Despite the importance of needs assessments in the context of providing patient-centered services, we were unable to find references to additional measures. This is clearly an area of great importance, with many opportunities for measurement-related PCOR. A learning service system cannot function without good needs assessment tools to identify appropriate and desired services and evaluate whether provided services met identified needs.

Therapeutic Relationship/Working Alliance As indicated in our discussion of stakeholder perspectives, consumers value continuity of care with clinicians with whom they have good working alliances. A wide variety of measures have been developed to assess these relationships, some of which have been shown to predict both short- and long-term outcomes,[57,58] although methodologically rigorous research that uses validated assessment instruments is needed.[57] In particular, research is needed to assess working alliance over time, beginning during early treatment.[57] This, too, is an area where current research suggests that improvements in the patient-centeredness of measures, which are then linked to patient-centered outcomes, could be used to assess system performance.

Adverse Effects: Diagnosis, Treatment, and Coercion One of the most important potential contributions of consumer-centered and consumer-directed research is in the area of unintended and adverse effects of diagnosis, treatment, and coercion. While considerable attention has been paid to medication side effects and social stigma, the research evidence on treatment-related trauma, self-stigma related to diagnosis and treatment, and disruptions in social relationships related to treatment is limited. In particular, concerns have been raised about devaluation by oneself and by others following diagnosis, and links between these experiences and negative outcomes, such as demoralization, income loss, and unemployment.[638]

Effects of labeling and subsequent devaluation may be accentuated by adverse effects associated with antipsychotic medications and the consequences of those effects, including poor medication adherence, worsened QOL, and increased stigma,[639] in addition to serious negative health effects.[349,640] For example, Seeman[92] argued that antipsychotics, as a group, increase weight and may lead to dry mouth and bad breath, cataracts, hirsutism, acne, and voice changes; they may also disturb symmetry of gait and heighten the risk for tics, spasms, and incontinence. Each of these side effects has the potential to undermine a person's attractiveness and acceptability to others and thus may contribute to discrimination, self-stigma, social withdrawal, and disengagement from treatment. She proposed that clinicians consider these factors when prescribing, and jointly discuss and monitor preventive and therapeutic strategies. While much of the attention paid to side effects has concerned their impact on health status, Seeman makes a powerful argument for including body image and social capital as patient-centered outcomes. Evidence showing a negative association between diagnoses of mental illnesses and social capital support this contention,[641] but additional research is needed to develop appropriate measures of social capital for individuals with mental health problems.[642] Similarly, body image has mostly been studied as a symptom or indicator of pathology, particularly in schizophrenia. The B-WISE is an exception,[643] but additional work is clearly needed to develop patient-centered measures of body-image outcomes.

Hamer and Haddad[639] reviewed data on adverse effects of antipsychotic medications, finding that inconsistency in reporting adverse effects was a significant barrier to making cross-study comparisons. They called for standardization in reporting, noted the importance of assessing service users' subjective experience of medications, and suggested that total medication discontinuation rates could provide a useful "global outcome measure" that incorporates both tolerability and efficacy. Little is known, however, about the relationship between this measure and service user preferences related to medications.

Equally important are measures of coercion. Results from the MacArthur Coercion study suggest that individual experiences of coercion among those who are pressured to enter the hospital or involuntarily admitted are strongly associated with the degree to which the process is characterized by "procedural justice."[87] Procedural justice was defined as having a voice, and being treated by family and clinical staff with respect, concern, and good faith during the process of hospital admission. In addition, this group has developed validated measures of coercion and coercion-related experiences.[644–645] Research is needed to evaluate best approaches for routine use of such measures as patient-centered outcome and indicators of system performance.

Stigma Stigma is an important concept and an insidious force among people with mental illnesses.[647] Stigma has been attributed to and associated with a wide range of attitudes, behaviors, circumstances, health conditions, social influences, and outcomes, including QOL, self-esteem, self-appraisal of competence, recovery, empowerment, social support, social integration, psychiatric symptoms, anxiety, avoidance/withdrawal, medication adherence, secrecy, and social and psychological functioning.[647–653] Pescosolido et al[654] elucidate the ways in which stigma comes to be defined in, and enacted through, social interactions, making clear that while stigma *attaches* to individuals, individuals do not develop beliefs and attitudes in a void but rather are influenced by a host and range of social, economic, cultural, and political contexts that shape expectations and cognitive processing. This framework[654] articulates the ways in which these contributing factors interact to produce stigma and discrimination, incorporating a wide range of theoretical constructs from labeling theory, social network theory, the limited capacity model of media influence, the social psychology of prejudice and discrimination, and theories of the welfare state.

There appear to be three interrelated levels of stigma: social, structural, and internalized.[647,654] At the social level, large groups or societies support stereotypes about and against a particular subgroup of people, which may be enacted through discriminatory practices, including by clinicians.[655] Structural stigma exists in the world of policies, laws, rules, and procedures that restrict the rights of the stigmatized group. At the individual level, internalized stigma is described as a process by which people in the stigmatized group believe or ascribe to stigmas endorsed by social groups and/or structural processes and perceive themselves as devalued. Theorists also differentiate between "felt" stigma—the awareness of negative perceptions of having a mental illness—and "self" stigma—defined as internal acceptance of negative stereotypes. Both felt and self-stigma can lead to avoidance of mental health–related services[656,657] and can negatively affect recovery outcomes.[625,647] Peer-support and peer-delivered services are intended, in part, to counteract self-stigma by providing role models to transform individuals from disempowered "patients" to empowered "persons." Additional research is needed, however, to conceptualize the processes by which this transformation takes place, as well as to develop best approaches for providing peer-delivered services.

In a 2010 systematic review, Livingston and Boyd[647] evaluated the effects of internalized stigma on people with mental illnesses, examining the relationships between stigma and sociodemographic, psychosocial, and psychiatric factors. The authors found that while none of the sociodemographic variables showed consistent significant relationships with internalized stigma for people with mental illness, psychosocial variables—including hope, self-esteem, empowerment/mastery, self-efficacy, QOL, and social support/integration—were all significantly and negatively associated with internalized stigma. Findings related to psychiatric variables were mixed. Symptom severity, the most studied variable, was positively associated with internalized stigma, while treatment adherence had negative associations. None of the other psychiatric variables, which included diagnosis, hospitalizations, illness duration, insight, treatment setting, or functioning and medication side effects, was found to have significant associations. The authors concluded that internalized stigma has negative effects on a wide range of outcomes.[647]

Other researchers have studied the ways in which internalized stigma affects recovery. Yanos et al[625] and Lysaker et al[649] have consistently found that internalized stigma negatively affects hope and self-esteem. They have also developed promising interventions to ameliorate self-stigma that involve service user narrative techniques along with other reflective and reconstructive approaches. Lysaker[658,659] and Vauth[660] examined how the evaluative dimension of self-concept (self-efficacy and empowerment) mediates psychological effects of self-stigma and coping with stigma. Their findings suggest that an avoidant coping style is a risk factor for anticipatory stigma, which erodes self-efficacy and empowerment.

Summary and Implications We know more about the origins and production of stigma and self-stigma than we know about how to ameliorate stigmatizing beliefs and discriminatory behaviors among service providers, or how to reduce self-stigma and the effects of discrimination among service users. Research is needed addressing the potential for prevention of treatment-associated self-stigma and disempowerment, including evaluations of the effects of peer-provided services and recovery-focused practices. Additional attention is also needed to develop programs for helping individuals with serious mental illnesses to overcome the negative effects of stigmatizing and discriminatory experiences, including enhancing hope, reducing self-stigma, and increasing self-esteem.[626]

Medication Satisfaction and Medication Side Effects Because psychoactive medications often have unwanted and unpleasant side effects, medication nonadherence is relatively high, particularly among service users with schizophrenia.[461] Conversely, having a positive attitude about medication has been associated with reduced symptoms, greater adherence to medications, and better community functioning.[661,662] A good understanding of satisfaction and satisfaction-related measures is, therefore, needed,[663] along with development of effective medications without problematic side effects.[459]

A number of researchers are developing assessments of medication satisfaction. A new study by Mojtabai et al[664] presents psychometric properties of the 40-item Patient Assessment Questionnaire (PAQ), which includes self-reported medication side effects. Development of the PAQ included patient focus groups, and the measure is intended as a patient-centered assessment of treatment effectiveness. The overall instrument was determined to have acceptable feasibility, interitem consistency, and construct validity for individuals with schizophrenia spectrum disorders. The five subscales, one of which assessed medication side effects, were demonstrated to have robust convergent and discriminate validity.

A single-question approach has also been validated. Vernon et al[665] found that an item assessing satisfaction on a seven-point scale had acceptable reliability and validity, was easy and viable in clinical research, and was potentially useful for clinical practices. Schizophrenia Care and Assessment Program Health Questionnaire by Lehman et al[666] included four questions assessing medication side effects, three of which have acceptable internal consistency (feeling tired and sluggish, interferes with normal thinking, and feeling fidgety or restless) and acceptable test–retest reliability.

The Satisfaction with Antipsychotic Medication scale[663] is a 33-item instrument that was developed by professionals and tested on 787 service users. Although the instrument had good internal consistency and acceptable consensual validity, the 40% response rate to the questionnaire suggests that service users may not have found it acceptable. Alternatively, the Treatment Satisfaction Questionnaire for Medication (TSQM)[667] was based on a formal conceptual framework, extensive literature review, and input from service user interviews that were used to select the most relevant questions for a diverse population with chronic illnesses. This 14-item self-administered questionnaire includes side effects, effectiveness, convenience, and global satisfaction. It is reliable and valid and was able to distinguish satisfaction based on method of administration, severity of illness, and length of time on medication. The results also suggested that the TSQM may be a good predictor of medication adherence for different medications and populations.

Gerber and Prince[668] evaluated a 35-item survey of satisfaction/dissatisfaction with several treatment-related factors among ACT program clients. They found dissatisfaction with medication side effects (38%), amount of medication (36%), demands of treatment (31%), the extent of clients' influence over treatment (30%), whether the client's opinion was considered in planning treatment (23%), and receipt of information about treatment options (20%).

Summary and Implications The studies above suggest that measuring medication satisfaction can be relatively easy and may have potential to enhance patient-centered outcomes (if such measurement is tied to clinical practices that address findings about satisfaction and dissatisfaction). Instruments developed using consumer feedback enhance the patient-centered aspect of these tools. Links between measurement, clinical responses, and outcomes remain to be established.

Summary and Implications for Patient-Centered Outcome Measures The measures reviewed in this section represent examples of measures that are, or could be developed into, patient-centered outcome indicators. Few have been used broadly or as performance indicators, and little is understood about how they might be used in aggregated fashion across service users and systems. Moreover, we do not know which factors and measures are most important to different stakeholders—service users, providers, organizations, and systems—nor do we understand the mechanisms by which care and services affect most of these outcomes. A great deal of research is needed to further develop patient-centered outcome measures, to link measures to delivered services, to assess the ability of those measures to detect treatment and recovery-based improvements, and to determine which of these outcomes and process indicators are most useful for providing feedback to improve system functioning. Finally, we reviewed no measures that are designed to incorporate individually tailored treatment outcomes, and these are sorely needed.

The Continuum of Patient-Centered Outcomes to More Traditional Clinical Performance and Outcome Measures The intent of our focus on patient-centered outcomes is not to suggest that other types of clinical and performance measures—or research targeting such measures—are of limited value. We believe these other measures are important to a broad range of stakeholders, and many may be considered valuable by consumers. For example, hospitalizations and rehospitalizations are costly to systems providing care and are patient centered in that they are undesirable outcomes for most consumers. Similarly, structural performance measures such as the availability of (or links to) evidence-based services such as supported housing, employment, education, and other psychosocial services can be important ways to assess the capacity of systems[609] and changes made in available services over time. Other examples of broadly valuable measures include monitoring of dosages of prescribed medications, polypharmacy and medication interactions, routine medical monitoring of medications and medication-related risks and side effects (eg, metabolic consequences of atypical antipsychotics, lithium levels), follow-up after hospitalization, screening for substance-related problems, and time to first visit following request for treatment. In addition, scientific advances may provide opportunities to develop additional measures that bridge gaps between what have traditionally been considered clinical measures and those that are more patient centered. For example, a project consultant suggested the following (G. E. Simon, personal communication; October 2, 2012):

> We need a new generation of fundamentally different measures. Traditional "clinical" measures are based on notions of diagnoses and symptoms. It is becoming increasingly clear that those diagnostic categories (like depression, bipolar disorder, schizophrenia) are simply "useful fictions" rather than true categories. And what we think of as symptoms are really epiphenomena of underlying differences in specific neuropsychological function (i.e. "anhedonia" is the surface manifestation of measurable differences in the anticipation of and response to reward [see the NIMH RDOC project for a description (http://www.nimh.nih.gov/research-funding/rdoc/index.shtml)]. This may sound far removed from service system issues, but it is not. Outcomes that reflect how people's brains/minds actually function are likely to be much closer to what patients/consumers care about than are outcomes that reflect what providers observe.

In sum, what we propose is that, no matter the source or type of outcome measure, service users should be asked for their opinions about the value, *to them*, of such measures. We believe they should be asked to identify measures they think should be used to assess their progress over time, and to be involved in identifying key indicators of good system and clinical performance. Then, performance and clinical measures should be linked to, and evaluated by, their ability to affect the outcomes that service users value the most.

Innovative Methods With Potential for Developing Patient-Centered Outcomes

Goal Attainment Scaling Goal attainment scaling is a method for evaluating progress toward individualized goals. The first step of the procedure is to construct goals for each patient that are observable and measurable. The second step is to rate each patient's progress on those goals. A total score across the goals is created and standardized. Goals can have differential weighting in this total score. Results from current goal attainment scaling approaches are difficult to compare across individuals because the goals, weightings, and anchors differ across individuals.[669] These difficulties might be overcome, however, and if they were, the advantage of goal attainment scaling is that it is person centered with individualized goals that are designed to represent realistic expectations for each person.[670] Creating a measure that captures the person centeredness of goal attainment scaling but can also be aggregated across individuals, providers, and health systems may be possible and could provide enormous benefit in a learning service system.

Willingness to Pay Willingness to pay (WTP) is a tool for determining those outcomes of greatest value to patients or other stakeholders. Participants are asked, by survey, how much they are willing to pay for specific treatment outcomes. The WTP technique is considered a comprehensive measure of value that theoretically includes the respondent's value for both direct and indirect costs, including intangible costs such as pain and suffering. Advantages of WTP as a valuation technique are its flexibility across different stakeholder groups and its ability to estimate the value of treatment for those other than the treated individual, usually referred to as "nonusers" in this literature. A study by Mulvaney-Day[669] examined the utility of WTP as a tool to assess family members' perspectives on mental health treatment, finding it a useful tool. Additional research using WTP with patients might be helpful in assessing what is of greatest value when it comes to treatment outcomes.

Discussion and Conclusions

In producing this report, we have repeatedly been confronted with gaps and disconnects—between how services are structured and funded and the needs of consumers; in the processes of service delivery across settings and over time; between the services that are delivered and the services consumers want and need; in knowledge about the effects of services (or the lack thereof) on consumer outcomes; and between traditional clinical outcome measures and the outcomes favored by the individuals receiving care. There are also significant disconnects between the perspectives of providers, families/carers, and researchers, and the perspectives of the consumers/patients they desire to serve. If this does not describe a system that is broken, it certainly describes a system that is not functioning as it should.

We were, thus, faced with a difficult and multipronged task: (1) to develop, based on existing resources and knowledge, a new vision of what care should be for people with serious mental illness; (2) to describe a system in which such care can be delivered in a patient-centered manner that is responsive to service user preferences and patient-centered outcomes; and (3) to suggest research questions, based on current knowledge, to move the system from its current state toward this newly envisioned state. In sum, we were faced with the need to develop innovative and emergent approaches to reduce the disconnects described above, building upon a flawed research base and gleaning as much useful information as possible from that base. As a result, this report, despite our best efforts, has no doubt perpetuated some of these same flaws.

With that caveat in place, we turn to our most important conclusions. Despite their rather significant implications, they can be summarized relatively briefly:

1. We lack sufficient outcome measures that have been (1) developed by or in concert with service users, or (2) evaluated rigorously by service users. Incorporating these measures into existing standard clinical assessments is essential to evaluating and improving the quality of services provided to individuals with serious mental illnesses. Development of these measures is crucial and should be a primary aim of mental health research in the near future.
2. Despite progress in recent years, information remains limited regarding the outcomes that service users value the most and least. More value-based information is fundamental to providing patient-centered care and measuring patient-centered outcomes. The next generation of mental health services research must develop a clear and representative understanding of the most common values among service users, cultural differences within and across these values, and the full range of these values.
3. Some attempts have been made to link individual outcomes to service packages, service characteristics (eg, continuity, therapeutic relationship), and performance measures, but consistency within and across outcome measures is lacking, and the measures used are fraught with problems when viewed from a patient-centered perspective. The mental health system needs feedback methods based on new patient-centered outcome measures that are causally linked to services, processes, and structures, and that are useful in one or more of the following ways:
    a. Measures that aid collaboration between service users and providers.
    b. Measures that, when aggregated across patients, are useful to clinicians as tools for assessing their own performance with the individuals they serve.
    c. Measures that, when aggregated across clinicians, are useful to organizations as tools for assessing performance, and in evaluating the effects of service packages and quality improvement efforts.
    d. Measures that, when aggregated across facilities and organizations, are useful to systems and policy makers for assessing overall performance and effects of modifications to factors affecting system functioning.
4. Most of the efforts to improve the quality of mental health services have focused on improving processes of care and ensuring the presence of institutional structures necessary to provide services. Links between patient-centered outcomes and measures of process and structure are nearly nonexistent. Such links must be established to more appropriately target changes in processes and structures that affect outcomes.
5. Very few efforts have been made to aggregate patient-centered outcomes data to provide performance feedback at the organization or system level. Aggregate use at the clinician level is very limited. Research developing solid measures that can be aggregated for use at all levels, and research developing effective methods for providing feedback using aggregated data, is sorely needed.
6. A vast array of interventions, targeting a wide range of service and treatment needs, has been developed for individuals with serious mental illnesses. Many show evidence of effectiveness as measured by conventional measures, but research is needed to compare their relative effectiveness using patient-centered outcome measures. Such studies must include real-world patients with complex problems, so that we know how to answer questions about best approaches of care given individual circumstances, while simultaneously providing necessary information to the decision makers who provide and finance care for these individuals.
7. Financing of care and services is complicated and structured in ways that prevent coherent, coordinated, and integrated service delivery. These circumstances also make comparisons difficult. Changes as a result of health care reform are providing opportunities for researchers to compare innovative methods of organizing and financing care. Researchers should take advantage of what are likely to be one-time opportunities.
8. As in other areas of the health care system, stakeholders may value and desire services that are not effective. Strategies, policies, and methods are needed for managing and communicating the results of CER in such situations.
9. In the context of systems, information alone is not adequate to produce system changes, although it is essential to the redesign processes. Complexity

science provides an alternative perspective, highlighting factors likely to produce system-level changes and subsequent improvements in the outcomes those systems produce. In particular, complexity theory suggests that the focus of quality improvement efforts should not be on methods of providing information or incentivizing providers or organizations, but rather on the culture and climate of organizations, how to support teams and employees in ways that allow them to flourish, and how to create structures that promote high-quality interactions and teamwork that allow patient-centered information to be used to its fullest. Such healthy interactions are viewed as the nexus of the information processing and sense-making that are the necessary foundations of, and motivations for, a learning system.

10. There is an inherent tension between (1) the needs and perspectives of researchers, quality improvement managers, policy makers, and clinicians, and (2) the needs and perspectives of consumers who desire subjective and qualitative assessment and individually tailored measurement. Methods and collaborative processes are needed to bridge these important gaps.

We challenge researchers studying comparative effectiveness and patient-centered outcomes to develop methods that incorporate the perspectives of service users for unique and individualized assessment, intervention, and outcomes. At the same time, researchers must produce the evidence necessary to allow the mental health care system to improve the services it delivers to individuals with serious mental illnesses and the outcomes those services seek to address.

The key CER and PCOR questions distill around identifying what constitutes patient-centered services; developing methods for collecting, aggregating, and distributing information about patient-centered outcomes; fostering organizational climates, cultures, and teamwork that lead to improved services and outcomes; and establishing concordance between services delivered and outcomes that service users value.

Opportunities associated with health care reform are abundant, and the business-as-usual approach to improving outcomes through incremental efforts is no longer viable. Researchers, administrators, policy makers, and clinicians are at a crossroads. It is time to take on the challenge of producing learning systems that can provide patient-centered and patient-directed care to individuals with serious mental illnesses.

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