Consumer Integration and Self-Determination in Homelessness Research, Policy, Planning, and Services

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Abstract

In this paper, the authors assess how the process and outcomes of research, policy, and service delivery change when they involve or are driven by people who have themselves experienced homelessness. They review the available evaluation literature and present lessons from the field on consumer integration in research, policy, and program implementation. Barriers to consumer integration and strategies for addressing these barriers are described. Barrow and her colleagues further address what happens when people who are homeless make the decisions about the housing and services they need. They conclude by reviewing findings on the individual- and system-level impacts of consumer-driven approaches to homeless assistance.

Introduction

In the 35 years since homelessness emerged as a social issue requiring public attention and policy responses, it has become institutionalized in government and civil structures at all levels. So many federal agencies are affected by issues related to homelessness that an interagency council has been created to coordinate their efforts. Our largest cities have full-blown homeless services departments; many not-for-profit agencies are wholly or heavily funded by contracts to provide housing and services to people who are homeless; and a cadre of academics now specialize in homelessness research. Against this background, the new language of "ending homelessness" announces a disruption of business as usual and issues a challenge to decades of conventional wisdom. Among the new approaches commanding attention are those that claim prominent roles for people who have been homeless—long the objects, but rarely the authors, of either research, policy, planning, or services developed to address homelessness or their own housing and service options.

This paper seeks to contribute to this Symposium's appraisal of knowledge about preventing and ending homelessness by addressing two questions: How are research, policy, and service delivery processes and outcomes changed when they involve or are driven by people who have themselves experienced homelessness? And what happens when people who are homeless make the decisions about the housing and services they need? Guided by these questions, we offer a synthesis and assessment of available information—some of it in the "fugitive" or "gray" literature of reports, newsletters, conference handouts, and web postings; some in peer-reviewed and published research—reporting on the involvement of people who are or were homeless in research, policy, planning, service delivery, and on consumer-driven, choice-based homeless services.

For the purposes of clarity in this paper, we use the term "consumer" to describe individuals who are currently or were formerly homeless. The term is controversial for several reasons, including its connotation that those experiencing homelessness can shop around for services among several available options as well as its links to an economic language of the marketplace. However, in the literature we review, it is the term most widely used to refer to people with current or past experiences of homelessness or those who have received system services. Other terms sometimes used instead of "consumer" in the mental health movement include "psychiatrically disabled" (Hensley, 2006) or "survivor" to indicate people who consider themselves "disabled" or who have survived psychiatric hospitalization or other trauma. However, these terms apply less broadly, since not all individuals impacted by homelessness have a history of psychiatric illness or hospitalizations or identify themselves as survivors of trauma. The term "peer" is currently used in the United States to identify people with a collective experience (for example, mental health and/or substance abuse recovery or homelessness) who are working and using their personal experiences and skills to assist others facing the same challenges. When reporting on programs that use the term "peer" in describing their staffing, we have retained this usage, but because we document participation by people who have experienced homelessness in research, policy, and planning, as well as in service delivery, the term "consumer" is a better fit than "peer" with the topic and intent of most parts of this paper.

Institutional and Policy Context

Decisions about and funding for research, policy, planning, and service delivery occur at national, state, and local levels, and are implemented in public, not-for-profit, and private organizational contexts. Several national-level government and advocacy organizations, notably the Interagency Council on Homelessness and the National Alliance to End Homelessness, have now adopted consumer-driven approaches as part of their push for 10-year plans to end homelessness, introducing choice-based housing and services in diverse locales. The National Association of State Mental Health Program Directors promotes state-level support for consumer self-determination of housing and services (NASMHPD, 2005).

Within federal departments that make policy and fund homelessness research, housing, and services, some agencies have strongly advocated consumer involvement. In the Department of Health and Human Services (HHS), the Substance Abuse and Mental Health Services Administration (SAMHSA), which supports homeless services for people with mental health and substance problems and evaluates innovative approaches, has played a leading role. The Health Resources and Services Administration (HRSA) has set high standards for consumer participation in governance of community health centers, though less stringent standards apply to HRSA-funded Health Care for the Homeless programs. At the National Institutes of Health (NIH), which fund most academic research on homelessness, consumer

involvement has not been a priority. The Department of Housing and Urban Development (HUD) has endorsed consumer involvement in continuum-of-care (CoC) planning and in the implementation of Homeless Management Information Systems (HMIS). A HUD pilot program to develop consumer roles in HMIS led to a national training initiative on consumer involvement in HMIS implementation.

Changes Since 1998

In the last decade, a wave of initiatives and actions has involved consumers in research, policy, planning, and service delivery; given increased prominence to choice-based approaches to housing and services; and created a growing body of supporting research evidence. The current momentum of consumer-driven programs and expansion of consumer roles emerged in the context of broad social changes limiting the use of public resources to address poverty and homelessness. Activism driving consumer involvement arose from the consumer/survivor movement in mental health services and has carried over into homeless services and advocacy. Concerns about HIV/AIDS, managed care, and a shrinking safety net have also been energizing forces. Even under unlikely social conditions, consumers and their allies have found ways to advance a more consumer-centered agenda in homelessness policy and services.

The context for these developments is complex. Several broad social trends have converged in the last decade to force a reassessment of approaches to homelessness:

- Reduced public commitment to social spending has coincided with losses of affordable housing, growth of wealth and health disparities, escalating incarceration of minority and disabled individuals, and a failure to stem the growth of homelessness.

- Penetration of market principles and management technology into health care and public services has produced managed behavioral health care (Mechanic, 1999) as well as new attention by public agencies and providers to cost saving, outcomes-based management, and evidence-based practice (Nelson et al., 1995); at the same time, demands for "personal responsibility" on the part of vulnerable groups have increased (Bishop & Brodkey, 2006).

Even as these processes reflect and promote reductions in social welfare spending, consumers have turned them into new openings for activism:

- Consumers have adopted and reframed calls for personal responsibility to emphasize individual choice, encouraging people to act as agents on their own behalf (National Mental Health Consumers' Self-Help Clearing House, n.d.).

- The recovery paradigm in mental health, promoted by the consumer/survivor movement and its allies, is challenging old assumptions about capabilities of consumers and making recovery, self-determination, and choice defining principles (Anthony, 2000; Campbell, 2006a; Mueser et al., 2002).

- Recovery has entered the federal mental health agenda (New Freedom Commission, 2003; SAMHSA, 2005c; US Department of Veterans Affairs, 2005).

- Consumer-operated programs and choice-based program models (Campbell, 2006b; Teague et al., 2006; Tsemberis et al., 2003) are being developed, tested, and disseminated.

- Ten-year plans to end homelessness are expanding opportunities for consumer-focused and choice-based approaches.

Synthesis of the Literature: Findings and Discussion

The Nature of the Evidence[1]

We focus on two bodies of literature. One describes the roles consumers are undertaking in research, policy, planning, and service delivery; the other considers the evidence for choice-based, consumer-centered housing and service programs. Both bodies of literature include primary documents; Web sites; descriptive material on meetings, trainings, policies, and programs; research reports; conference proceedings; journal articles; and book chapters. The literature varies in the extent to which it is research-based and in the type and rigor of study design and methods. Research includes qualitative studies, surveys, case studies, controlled quasi-experimental outcome evaluations, and randomized clinical trials. Its focus also varies: people who are homeless versus related groups such as consumers of mental health services—who may or may not be homeless; or interventions aimed at homelessness versus those addressing clinical outcomes, employment, well-being, or recovery.
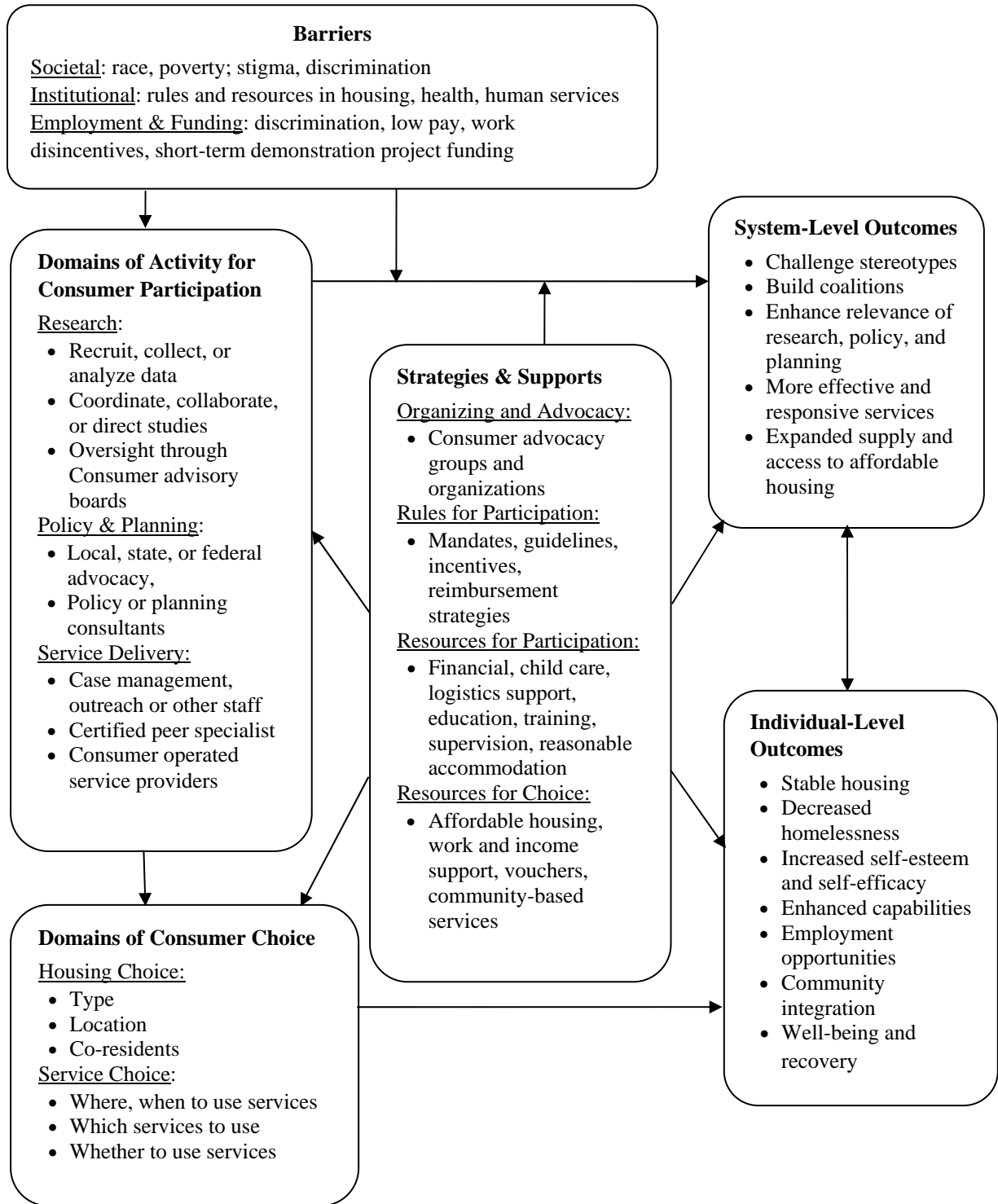
Although work in these two areas has proceeded independently, we argue that they are best understood as two dimensions of an overarching theme that is expressed in such concepts as self determination and agency. The first dimension (consumer involvement in research, policy, planning and service delivery) is concerned with consumer participation in the collective deliberations and actions that determine how homelessness is understood and addressed; the second focuses on identifying and assessing the

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[1]   The use of evidence-based practice (EBP) has become a well-established goal in social services, health care, and mental health services. Varied research designs (ranging from qualitative descriptions to various kinds of quasi-experimental research) can provide initial support for a promising practice. However, services are usually designated as "evidence-based" only if rigorous, randomized controlled trials (RCTs) demonstrate that the people they serve have better outcomes (for example, longer periods in stable housing) than similar people who did not receive such services. Because RCTs randomly assign participants to either experimental or alternative services and compare their outcomes, they can provide strong evidence that a practice actually causes good outcomes. The highest form of evidence, "meta-analysis," combines data from several RCTs of the same intervention (Institute of Medicine, 2001; Sackett et al., 2000).

Although we highlight instances of "higher level" evidence, such as RCTs, a growing literature contests uncritical acceptance of EBP criteria. Critics note that RCTs test interventions in populations and conditions rarely matched in the real world (as when studies of services for people who have experienced homelessness and psychiatric disabilities exclude those with co-occurring disorders); understudied approaches may not attract funding and thus have little chance to develop an evidence base; and EBPs often use a limited notion of "what works" (Sanderson, 2004; Tanenbaum, 2005). These critiques resonate with advocates of recovery-oriented services who worry that peer services may be undermined by random assignment and that experimental methods and existing measures fail to capture meaningful but hard to measure processes and goals (Anthony, Rogers, & Farkas, 2003; Clay, 2006; Jewell, Davidson, & Rowe, 2006).

As the uses of EBP expand from aiding clinical decision-making to guiding policy, further objections have been registered by those who understand policy-making as a process that incorporates considerations of power and values (e.g., the power to set research agendas; assumptions about valued outcomes) in addition to evidence-based understandings of "what works" (Nixon, Walker, & Baron, 2002). These concerns have particular relevance to consumer involvement in research, policy, and planning, where available metrics for assessing "outcomes" may not take appropriate measure of the goal of changing the balance of power between consumers and those who shape the policies that affect them.

Exhibit 1 Consumer Integration and Self-Determination

Barriers

Societal: race, poverty; stigma, discrimination
Institutional: rules and resources in housing, health, human services
Employment & Funding: discrimination, low pay, work disincentives, short-term demonstration project funding

Domains of Activity for Consumer Participation

Research:
- Recruit, collect, or analyze data
- Coordinate, collaborate, or direct studies
- Oversight through Consumer advisory boards

Policy & Planning:
- Local, state, or federal advocacy,
- Policy or planning consultants

Service Delivery:
- Case management, outreach or other staff
- Certified peer specialist
- Consumer operated service providers

Strategies & Supports

Organizing and Advocacy:
- Consumer advocacy groups and organizations

Rules for Participation:
- Mandates, guidelines, incentives, reimbursement strategies

Resources for Participation:
- Financial, child care, logistics support, education, training, supervision, reasonable accommodation

Resources for Choice:
- Affordable housing, work and income support, vouchers, community-based services

System-Level Outcomes

- Challenge stereotypes
- Build coalitions
- Enhance relevance of research, policy, and planning
- More effective and responsive services
- Expanded supply and access to affordable housing

Individual-Level Outcomes

- Stable housing
- Decreased homelessness
- Increased self-esteem and self-efficacy
- Enhanced capabilities
- Employment opportunities
- Community integration
- Well-being and recovery

Domains of Consumer Choice

Housing Choice:
- Type
- Location
- Co-residents

Service Choice:
- Where, when to use services
- Which services to use
- Whether to use services

effectiveness of service and housing configurations that maximize individual choice and control among people who experience homelessness. Exhibit 1 offers a provisional model of the how these are related and the barriers and strategies that influence individual outcomes and system-level change.

We begin this review with a discussion of consumer involvement in research, policy, planning, and service delivery. To document *consumer involvement in research*, we draw on both publications describing consumer experiences in new research roles and studies that evaluate consumer performance as interviewers or assess the quality of research using participatory approaches. When we turn to *involvement in policy and planning*, there are no formal evaluations. The evidence lies in position papers, minutes of meetings posted on Web sites, conference slideshow presentations, and a few published conceptual articles. In contrast, work on *consumer involvement in service delivery* encompasses qualitative descriptions based on observations, focus groups, and interviews; quasi-experimental studies of effects of consumer staff on client outcomes; and randomized trials of consumer-delivered interventions.

Within each domain of involvement, our review documents both the roles consumers are assuming and the strategies that they and their allies have developed for moving beyond token participation toward full integration. We conclude the review of consumer integration in research, policy, planning, and service delivery with a discussion of common barriers that obstruct this effort, both at the societal level and within each domain's institutional structures, and current or proposed approaches to addressing them.

Since the purpose of consumer involvement in research, policy, planning, and service delivery is to ensure that decisions in these domains incorporate the experiences, perspectives, and preferences of those whose lives they affect, integration should lead to enhanced self-determination for individuals who are experiencing homelessness, creating the conditions for expanding their options and honoring their choices. In the second part of the paper we review the literature on choice-based services and housing. Here we describe surveys of housing and service preferences of people who are homeless and a number of quasi-experimental studies and randomized trials of a consumer-driven housing first model of supported housing. Other choice-based approaches are yet to be studied systematically, though we cite descriptive accounts of emerging practices.

Consumer Roles in Research, Policy, Planning, and Services

Reasons for Consumer Involvement

In her preface to a report on an advocacy and organizing project entitled *Adding Seats to the Table: A Community Based Approach to Family Homelessness*, Bassuk (2001) describes the project's emphasis on providing resources and support that enable families to shape the programs and policies that affect them as both the *right thing* and the *smart thing* to do. While briefs for involving consumers in research, policy, planning, and service delivery refer to both the ethical imperative (the right thing) and positive effects on service outcomes and consumer well-being (the smart thing), in an era of outcomes-based management and evidence-based programming, literature on consumer involvement increasingly argues wisdom rather than righteousness. Indeed, this paper focuses on compiling and assessing the research support, as demonstrated by improved outcomes, for the contention that involving people who have experienced homelessness and respecting their preferences and choices produces more relevant and effective services.

However, the fervor to demonstrate that consumer involvement is "smart" should not obscure compelling ethical and social justice reasons for promoting it. Boote and colleagues (2002), in a review of consumer

roles in health research, ask if consumer involvement is "fundamentally about increasing the quality and user satisfaction of the end product … or does it relate more to the empowerment of users and the democratization of the research process?" Their analysis suggests that the former goal emphasizes satisfaction and value for money, but typically entails passive strategies (e.g., satisfaction surveys, consultation) to respond to consumer demands and "does not necessarily include an obligation to enable consumers to make those demands" (Boote, Telford, & Cooper, 2002, p. 223; see also Salzer, 1997). In contrast, approaches like "participatory research" and "action research" can be a means for changing power relations and advancing equity and social justice.

A similar contrast is evident in approaches to managed care. One approach emphasizes efforts to involve consumers in support of managed care goals, recommending practices that will further quality assurance and persuade consumers of the legitimacy of cost containment, priority setting, and care rationing by managed care providers (Sabin & Daniels, 1999; 2001). In contrast, a legal advocacy guide frames consumer roles in contracting for managed care as a struggle for rights and justice involving contention with "other stakeholders … [who] are well-represented by powerful groups and can exert great influence on how the managed care contract is written, but their interests do not always overlap with those of consumers" (Bazelon, 1998, p. 11).

Although Boote and colleagues focus on consumer roles in health research, and the legal advocacy guide on consumer roles in contracting for managed care, the issues raised also apply to homelessness research and policy. Both the stigma of homelessness, with its associated barriers to services and personal opportunity, and the magnitude of power differentials between those experiencing homelessness and those who design and implement research, policy, and services demand particular attention to issues of social exclusion and "a special moral imperative" to involve consumers in planning and services (Rowe, 2007).

Philosophy and social theory provide a foundation for considering consumer self-determination and integration as essential for social justice. Fraser uses examples of race, gender, and sexual orientation in arguing that overcoming social injustice requires "participatory parity," that is, full inclusion in the process of determining how resources are distributed and diverse identities are valued (Fraser & Honeth, 2003). For Sen (1999) and others (see Hopper, in press; Nussbaum, 2000; Olsen, 2001) who use his concept of "capabilities" to characterize the combination of capacities and resources that enable people to achieve valued roles and identities, social injustices related to poverty, gender, race, and disability all entail capability deprivation. Redress requires organizing resources to ensure both well-being *and* the exercise of agency or self-determination (Sen, 1999; Hopper, in press; Nussbaum, 2000; Olsen, 2001). Social justice arguments for participatory parity and agency lend philosophical weight to the claim that fostering consumer integration is the "right" as well as the "smart" thing to do.

Strategies for Consumer Involvement in Research

Glasser's review of consumer involvement (1999) only briefly mentioned research roles for people with experiences of homelessness. Recently, in large multisite studies, people with experiences of homelessness, mental illness, and addiction dependency have been employed as recruiters, interviewers, or trackers and in administrative and coordinating positions—sometimes only after challenging researchers' stigmatizing preconceptions that consumers lacked ability to learn or use research skills or that their presence in research roles would destabilize others with mental illness (Campbell, 2006b; McMullin et al., 2006; Mockus et al., 2005).

Evaluations of consumer employment in homelessness research have not yet appeared in the literature; however, in studies of mental health services that employed consumers to administer treatment satisfaction surveys in both self-help and professional settings, interviews conducted by well-trained consumers met quality and accuracy standards (Howard & El Mallach, 2001; Lecomte et al., 1999), with small differences in responses to consumer versus professional interviewers (Nilsen et al., 2006). Consumer interviewers reported high job satisfaction, improved feelings about self, increased self-assurance, pride in working, high motivation, and new friends, despite the work involving difficult tasks and some stress (Lecomte et al., 1999).

Individual research centers and consumer-run agencies support consumer research involvement, but it has taken mandates from funding agencies to induce broader inclusion of consumers in academic research on homelessness. The Substance Abuse and Mental Health Services Administration (SAMHSA), with its several multisite services research initiatives related to homelessness, has been the institutional locus of much of this activity. An agency mission statement (SAMHSA, 2005a) emphasizes consumer involvement in all aspects of SAMHSA programming and includes a specific mandate that "[c]onsumers and families should be integrally involved in designing and carrying out all research and program evaluation activities. These activities include: determining research questions, adapting/selecting data collection instruments and methodologies, conducting surveys, analyzing data, and writing/submitting journal articles" (McMullin et al., 2006; SAMHSA, 2005a).

Making consumer participation a condition of funding has been an impetus for expanding consumer research roles. The process of implementing that mandate has revealed both barriers to effective consumer integration and strategies for addressing them. Based on experience in Phase I of SAMHSA's Homeless Families Program, a detailed "Guidance for Consumer Participation" advised applicants for Phase II on how to support consumer integration through selection, preparation, and compensation of consumers in the cross-site Steering Committee and local research projects (SAMHSA, 2001).

Through a series of SAMHSA initiatives (Supported Housing, Consumer-Operated Service Programs, Women with Co-occurring Disorders and Violence, Homeless Families Program), consumers have taken increasingly active roles as consumer panel (CP) members, as local site-based staff (recruiters, interviewers, trackers, data entry clerks, research directors, or principal investigators), as staff at the cross-site coordinating center that manages each initiative, and as participants in the cross-site steering committees that give scientific direction to the projects.

Publications policies initially recommended only that a CP member be present for cross-site presentations at professional meetings (SAMHSA/CMHS, 2000). Later initiatives addressed the need to support consumer travel and participation in such conferences (SAMHSA/CMHS, 2002), which allowed CP members to press for inclusion on study panels and to develop a proactive policy of submitting abstracts for presentations at national professional and policy meetings. Through presentations, journal articles, and books, consumers are reporting to both consumer and research communities their experiences and lessons learned about barriers to consumer involvement and effective strategies to enhance integration (Campbell, 2006a; Clay et al., 2006; McMullin & Reid, 2003; McMullin et al., 2006; Meyers, 2002; Mockus et al., 2005; Pennington & McMullin, 2004). McMullin and colleagues (2006), who described experiences of CP members in the Homeless Families Program, identified three sets of barriers to full consumer integration: tokenism; turnover in panel membership; and issues related to time, effort, and expense of

participation. They described 10 strategies that fostered effective consumer integration in this multisite project. (See Exhibit 2.)

Consumer panels for SAMHSA initiatives have documented a variety of research, service, and personal impacts of their involvement in research. The Homeless Families Program CP influenced conceptual models, study measures, data collection procedures, dissemination of study findings, and even theinterventions being tested (McMullin et al., 2006; McMullin & Pennington, 2005; McMullin & Reid, 2003). The Women with Co-occurring Disorders and Violence (WCDV) consumer panelists, identified as consumer/survivor/recovering (C/S/R) women, reported a strong impact on their study's instrumentation, particularly sections covering trauma and parenting, where they developed measures of the unaddressed aftermath of violence (Mockus et al., 2005). C/S/R women documented members' experiences through systematic debriefing interviews and focus groups, followed by qualitative thematic analysis, providing moving detail on the sometimes tense but ultimately rewarding process of finding a personal and collective voice and the individual transformations that ensued (Mockus et al., 2005).

Setting the research agenda. Although SAMHSA's initiatives provide a model for integrating consumers in various aspects of large multisite studies, consumers typically only enter the picture after a study's focus and design have been determined. In contrast, British health services researchers report that "consumers have been consulted, have collaborated and have controlled initiatives for setting research agendas across a wide range of topics in health and beyond," including homelessness. Consumers' impact is greatest when research organizations see political or commercial benefits and involve consumers in setting priorities, not just in assessing the merits of specific topics (EPPI-Centre, 2006). Moreover, "productive methods for involving consumers require appropriate skills, resources, and time to develop and follow appropriate working practices. The more … consumers are

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Exhibit 2

Strategies and Mechanisms Used to Foster Consumer Integration in the SAMHSA Homeless Families Program

Federally mandated consumer participation and support

- Coordinating Center consumer staff
- Consumer included in all aspects of programs
- Federal project officers address integration barriers

Financial support to cover consumers' expenses

- Payments for time and expertise
- Travel advances covering travel and childcare costs

Consumer staff

- Coordinate work of consumer panel
- Consumer liaison for researchers and consumers
- Study recruiters, interviewers, trackers, and data entry

Travel logistics

- Identify and address travel barriers
- Hotel check-in without credit cards
- Alcohol free rooms and receptions

Consumer panel meetings

- Share strategies to overcome integration barriers
- Develop recommendations for steering committee
- Small group discussions with federal project officers

Steering committee meeting logistics

- Define research jargon as used
- Allowing time for consumer questions and input

Bridge communication and cultural gaps

- Trainings by consumers on study topics
- Continually addressing integration barriers
- Forum on hiring consumers as research staff

Communication between meetings

- Staff identified to address consumer integration
- Hard copies of emails and materials sent to consumers
- Monthly conference calls to review study materials

Reducing turnover and increasing retention of consumers

- Mentoring of new consumers
- Development of consumer advisory boards

Training

- Orientation
- Cross trainings on study topics
- Research methods and how to read and interpret data charts

involved in determining how this is to be done, the more research programmes will learn from consumers and about how to work with them" (Oliver et al., 2004).

A report on consumer involvement in the peer review process for clinical research at 16 NIH Institutes determined that consumers routinely participated in review panels at 4 Institutes, and only occasionally at another 3. Institutes that routinely used consumers on review panels did so to obtain perspectives of target populations, expertise regarding the feasibility of interventions in real-world situations, and advice on issues related to the use of "human subjects." These Institutes offered consumer review panel members adapted or specialized training, and generally one or two consumers participated in each review panel. In the absence of participants' accounts or data on decision-making processes and outcomes, however, it is unclear whether consumer participation extended beyond tokenism (Bartlett, 2006).

Community-based participatory research (CBPR). Public health research has long used a variety of approaches (action research, participatory research) that seek more equitable partnerships between researchers and members of communities in which research is carried out (Lewin, 1946; Freire, 1972). These approaches have recently been conjoined under the rubric CBPR (community-based participatory research), which incorporates and codifies many of the defining principles of these approaches: participatory process, cooperative engagement of community members and researchers, co-learning, system development, and community capacity building. As an empowering process that can increase participants' control over their lives, CBPR seeks a balance between research and action (Minkler & Wallerstein, 2003; Bridgman, 2006).

A recent review of CBPR projects in public health reports that, despite uneven data on the research process, many projects achieved community involvement in setting research priorities and generating hypotheses; several described improvements in research quality (recruitment, methods, measures, dissemination) related to collaboration; and a large majority of intervention studies described improvements to the intervention related to the CBPR approach (Viswanathan et al., 2004). CBPR proponents have begun to create methods not only for developing such partnerships but for assessing their fidelity to CBPR principles.

Recently CBPR has begun to appear in the arena of mental health (Wells et al., 2006; Nelson et al., 2006) and homelessness research (Bridgman, 2006; Wang, 2003). CBPR has often involved prevention studies conducted in neighborhoods with limited access to resources for health and mental health care, and neighborhood-based advocacy groups have been primary vehicles for research/community partnerships. Challenges result from CBPR's incompatibility with research development and funding structures that require the research problem, study design, and methods to flow directly from theory and prior research findings, leaving little room for the co-learning process that occurs through negotiation of research agendas, hypotheses, design, and methods of particular projects. While HHS has solicited advice on adapting application and funding processes to accommodate CBPR approaches (Viswanathan et al., 2004), both research funding and academic cultures remain challenged by CBPR.

The role and impact of people with personal experiences of homelessness in designing and conducting research have changed significantly since Glasser's review (1999), but these achievements have emerged from hard-won struggles. Even in settings that are committed to bringing in consumers, integration has not been easily achieved. Consumers who perform this groundbreaking work, particularly in academic research settings, can find their positions are a source of contention among staff; their experiences of

homelessness are stigmatized; their voices are ignored; and a variety of subtle discriminations, such as the absence of interactions with co-workers outside the work environment and a closing of ranks when uncomfortable topics are raised, exclude them from full participation. At the University of Massachusetts-Boston's Center for Social Policy (CSP), an early interest in consumer participation led to the creation of a constituent coordinator position with a broad job description that included the responsibility to engage people experienced in homelessness and poverty. That the actual tasks of this position were usually restricted to project-based activities was largely due to funding challenges for constituent engagement projects. Challenges around staff acceptance of the shift to include consumers can inhibit substantive integration. The CSP strategy was to form an ad hoc committee of committed staff persons, which was tasked with operationalizing constituent involvement. Over an eight-month period, this group defined a spectrum of consumer roles, a process culminating in a formal constituent internship within CSP. This program, launched in January, 2007, provided an opportunity for a person experienced in homelessness and/or poverty to work in one of several apprenticeship areas: applied research, clerical/office support, communications/marketing, or any combination. One of the Center's collaborating partners, One Family Scholar Program, provided a candidate to fill the position.

McMullin and colleagues (2006) described a progression from consumer tokenism, through consumer involvement, to consumer integration. (See Exhibit 3.) They noted that consumers with experiences of homelessness, mental illness, addiction, and justice involvement encounter stigma, no less in research settings than in communities, service programs, housing, and employment. Members of SAMHSA consumer panels have identified several exclusionary aspects of research practice and culture, ranging from the financing and logistics of collaboration to the use of research language that alienates consumers or mystifies the very issues on which consumers are experts. Consumers have developed skills and strategies to overcome stigma and other barriers to effective participation in research, but without mandates and support from funders, academic communities are unlikely to gain the benefits of consumer expertise. Consumer integration in research is still in the early stages, but models of integration currently being developed and disseminated offer a platform for further expansion.

Exhibit 3

Consumer Tokenism, Consumer Involvement and Consumer Integration in Research

Tokenism	Involvement	Integration
1–2 consumers invited to participate in limited or superficial roles	Small number of consumers invited	Significant number of consumers from diverse populations actively involved
1–2 consumer expected to represent all consumer perspectives	Limited roles	Key positions including management, research staff, serving on steering committees or oversight boards
No concrete decision making authority	Limited decision-making authority	Decision-making authority
Mostly volunteer time	Some compensation for time and expertise	Competitive compensation for time and expertise

Strategies for Consumer Involvement in Policy and Planning

Consumer involvement occurs across the varied venues where homelessness policy-making and planning take place. While Glasser (1999) included examples of consumer advisory boards (CABs) and of consumer members of advisory boards, newer initiatives with consumers present in meaningful numbers and in multiple roles (e.g., as CAB members, staff, trainers, and consultants) allow discussion not just of consumer involvement but consumer integration.

Local advocacy. At a local level, consumer advocacy groups use organizing and lobbying strategies to impact policies; planning bodies hire consumer consultants and employees; and CABs serve in monitoring, consultative, and decision-making capacities for local government or health care organizations.[2]

Homes for Families is an advocacy organization that brings together families that have experienced homelessness (half of its staff and half of its board of directors have experienced homelessness) with service providers and advocates across Massachusetts to press for policy changes that address root causes of homelessness. Consumer perspectives have priority in the development of the policy agenda, which thus far includes developing prevention programs, expanding housing options, training leaders, and addressing economic and social justice issues (Homes for Families, 2006).

Other local advocacy groups (Family Housing Solutions in Trenton, New Jersey; Humanity for Homeless in Denver, Colorado; and Warriors for Real Welfare Reform in Hartford, Connecticut), with support from the Better Homes Fund and the W.K. Kellogg Foundation, conducted organizing activities with families in their communities, created forums for dialogue on homelessness with elected officials, developed newsletters and educational programs, influenced state welfare-to-work policies, joined other groups to develop a shelter, changed local criteria for housing eligibility, and obtained guaranteed participation in HUD grants (Better Homes Fund, 2001). It is difficult to attribute specific policy outcomes to consumer advocacy, but sponsors of the effort viewed organizing families as a viable strategy for community change. The project reported on both challenges and organizing lessons. (See Exhibit 4.)

Exhibit 4

The Better Homes Fund and W.K. Kellogg Fund Findings

Challenges	Organizing Lessons
Welfare and shelter regulations	Value of coalition-building
Residential instability	Active participation by families
Isolation	Leadership training
Shame	Supporting women's roles as mothers
Uncooperative social service providers	Strategies for leveraging policy change
Limited resources and capacity	Generating individual and collective empowerment

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[2]   Advocacy groups described here are documented in media coverage or in Web sites or reports. We suspect much consumer activism goes unrecorded.

Protests around local issues have spurred the development of advocacy groups founded and led by people who have experienced homelessness. Examples include Rhode Island's People to End Homelessness, an organization committed to ending Rhode Island's homelessness crisis through affordable quality housing. This group has organized several highly visible protests to draw attention to growing homelessness in the state (People to End Homelessness, 2006). In New York, Picture the Homeless has organized campaigns to modify approaches to subsidizing housing for people leaving shelters; end selective enforcement of "quality of life" regulations that target people who are homeless; address barriers to housing; and challenge discriminatory supermarket practices that target recyclers (Picture the Homeless, 2006).

National policies on consumer involvement in local policy and planning processes. Since most funding for local homeless services and housing comes from federal grants, many policies are shaped nationally but carried out locally. At a national level, consumers represent local CABs on national consumer panels, serve individually on policy and planning boards or workgroups, and are employed by federal agencies as consultants, trainers, advisors, or administrative staff for policy initiatives. We describe here several approaches to consumer involvement in these national/local interactions.

SAMHSA. SAMHSA's previously cited policy on consumer involvement in research and evaluation is part of broader *Guidelines for Consumer and Family Participation* in all aspects of SAMHSA policy and program development—and particularly in projects funded through its grant programs. This guide comprehensively details expectations for consumer involvement in organizations and programs receiving SAMHSA grants (SAMHSA, 2005a.) (See Exhibit 5.) SAMHSA's policy on cultural issues for funded research and programs is outlined in *Guidelines for Cultural Competence* and addresses issues of training and staffing, language, materials, evaluation, community representation, and implementation (SAMHSA, 2005b).

HUD Continuum of Care (CoC). HUD funding is a primary source of support for housing and service programs addressing homelessness. HUD requires local continuum of care (CoC) planning committees to prioritize needs and assemble a single comprehensive application from each locale. Although HUD has begun to standardize governing processes for CoC planning committees, expectations for consumer involvement remain non-specific: CoCs should have a planning body that is broadly representative of stakeholder interests, with 65 percent private sector representation, including consumers who are homeless, or explain why they do not. Local agencies may win points for demonstrating consumer involvement in their HUD programs, for example through CABs, satisfaction surveys, or tenant councils, and for involving consumers in program design and creation (New York City CoC, 2006).

HUD Homeless Management Information Systems (HMIS). Since 1999, HUD has provided standards and technical assistance to phase in local HMIS systems, mandated by Congress to document the extent of homelessness and service usage by individuals who are homeless. HMIS has become a vehicle for expanding consumer participation in policy and planning, as an initial pilot program for involving consumers in HMIS planning and implementation has evolved into a training initiative introduced in communities across the country. Consumer involvement varies. HMIS raises key issues for consumers—both as a mechanism for making their needs known and as a potential threat to privacy and confidentiality.

The earliest proposals for HMIS implementation evoked challenges from providers and advocates around privacy issues. Over time, however, consumer advocacy and consumer-designed trainings on HMIS have

Exhibit 5

Guidelines for Consumer and Family Participation in SAMHSA Grant Programs

Mission	Reflect value of involving consumers and family to improve outcomes
Planning	*Consumer and family members involved in substantial numbers in:* • Conceptualization of initiatives • Identifying community needs, goals and objectives • Identifying innovation approaches to address needs • Developing budgets • Incorporating peer support methods
Training and Staffing	*Consumers and family members included as staff* • Consumer and family members hired as staff with pay parity • Substantive training for staff in consumer and family issues
Informed Consent	*Recipients of project services* • Informed of benefits and risks of services • Make voluntary decisions to receive or reject services
Rights Protection	*Consumer and family members fully informed of all rights including:* • Information disclosure • Choice of providers and plans • Access to emergency services • Participation in treatment decisions • Respect and non-discrimination • Confidentiality of healthcare information • Complaints and appeals • Consumer responsibilities
Administration, Governance, and Policy Determination	*Consumer and family members:* • Hired in key management roles • Provide project oversight and guidance • Sit on all boards of directors, steering committees, and advisory boards in meaningful numbers • Fully trained and compensated for activities
Evaluation	*Consumers and family members integrally involved in designing and carrying out all research and program evaluation activities including:* • Determining research questions • Adapting/selecting data collection instruments and methodologies • Conducting surveys • Analyzing data • Writing and submitting journal articles

promoted consumer involvement as a means to strengthen privacy protection and enhance the benefits the system promises. The Center for Social Policy (CSP) at U-Mass-Boston, which initially was a lone voice for consumer involvement in HMIS, envisioned a system that would be informed in part by the people receiving services, as opposed to program administrators and policymakers only. The Center demonstrated that consumer involvement can be part of an HMIS implementation and, in fact, that implementation could not be as effectively achieved without consumer involvement. Encryption, humaneinterview protocols, consumer perspective on data findings, and HMIS peer-to-peer trainings proved invaluable to implementation. For example, peer training presentations done by CSP consumer

staff in conjunction with other stakeholders identified varied roles for consumers (e.g., as peer trainers; advocates; consultants; and leaders of or participants in steering committees, discussion groups, and advisory panels) and individual benefits of consumer involvement (e.g., skills development, enhanced professional and career choices, employment, leadership development, participation in community decision-making groups). This initiative is described as a point "where public policy, HMIS, advocacy, and ending homelessness on a personal and systemic level converge" (Tripp, 2004, 2005). The training became a national model for communities to follow in local implementations.

Health Care for the Homeless (HCH). Administered by HRSA, HCH supports 182 local projects that annually provide health services for over half a million people experiencing homelessness. Since 1987, HCH has mandated consumer involvement in project governance. Although HCH programs typically obtain waivers of HRSA's requirement that community health centers have consumer majorities on their governing boards, they must document alternative means to ensure meaningful consumer input into program governance, which has typically been through CABs. In 2003, HCH's National CAB (elected by local CAB representatives at HCH's annual national meeting) developed a Consumer Advisory Board Manual (Dailey, 2003) to guide individual HCH programs. (See Exhibit 6.)

HCH's National Council also contracted with an organizing and advocacy group for a pilot project that used consumer-based outreach to collect and analyze data from surveys with 249 consumers at 13 sites. The project recommended: making the outreach/survey process a routine activity for local CABs, with data aggregated at the national level and findings fed back to local projects and CABs; National Council funding to support increased consumer involvement in outreach and HCH governance; clarification of local CAB functions, with incorporation of CABs "into the 'lifeblood' of HCH" at every level; pursuit of the vision of majority consumer boards of directors within HCH projects; and support for local HCH staff to be more involved in community organizing and advocacy (Boden & Lozier, 2005).

Exhibit 6

Consumer Advisory Board Guidelines for Health Care for the Homeless Projects

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- Fit local projects needs
- Autonomous governance structure and procedures
- Clear organizational guidelines
- Membership represents all program constituents
- Conduct ongoing recruitment
- Support for meetings sites, facilitators, and transportation
- Strong relationships with governance boards and senior management

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Ryan White Care Act (RWCA) planning councils. The RWCA, administered by HRSA, provides funding of health and supportive services for people living with HIV and AIDS. Localities must coordinate their RWCA applications through local planning councils, which have decision-making authority over allocations of funds. RWCA bylaws for cities with the greatest concentrations of people with HIV/AIDS have specific requirements to ensure planning council membership is representative of local populations affected by HIV/AIDS. At least 33 percent of members must be individuals who self-identify as being infected with HIV, who reflect the demographics of the populations with HIV, and who are not employees, consultants, or board members of RWCA Title I provider agencies. Consumers have a significant voice in RWCA funding and service planning.

Effects of consumer involvement in policy and planning. While federal agencies have become more proactive in promoting or even mandating consumer involvement in homelessness policy and planning,

documentation and evaluation of individual and program or system impacts remains thin. First-person accounts of experiences in homelessness policy and planning settings describe service improvements as well as transformative effects on consumers who are active participants (Tripp et al., 2005). Such accounts, which have appeared in broadcast, newsletter, and slideshow formats, provide critical technical information for consumers and preliminary evidence for the impact consumers have on policies and planning.

One qualitative study in an HCH program in Houston used participatory action research to describe policy and planning involvement of CAB members (Buck et al., 2004). An analysis of agendas, minutes, and transcripts identified four prominent themes: operational practices, roles, and processes involved in achieving CAB goals; emergence of group and individual identities; the salience of power hierarchies not only between individuals who are homeless and staff at shelters or service agencies but within the population experiencing homelessness; and a need for more respectful and comprehensive services. CAB members launched a specific project to disseminate information about existing services. Observed and reported impacts on participants included acquisition of new skills for inquiry, planning, and relationship management.

Controlled studies of approaches to consumer involvement in homelessness policy and planning have not been conducted. A Cochrane Collaboration review identified three controlled studies of the effects of consumer involvement in health policy. One compared phone or face-to-face contact versus mailed surveys in a study of consumer health priorities, and two examined effects of consumer consultation on written educational material prepared for patients. The interventions involved "passive" strategies— consumer consultation, rather than collaboration or control—and narrowly defined outcomes (readability of material, rankings of health priorities). The studies had methodological weaknesses and showed only modest effects of consumer involvement, but the authors conclude that randomized controlled trials can be used to assess consumer involvement in health policy and planning (Nilsen et al., 2006).

Strategies for Consumer Involvement in Service Delivery

Consumer involvement in homelessness service delivery arose in part because mental health programs failed to reach some people with mental illness who were experiencing homelessness, creating a service need that consumer providers addressed (Glasser, 1999). Homelessness programs have also drawn on a tradition of mutual aid and peer staffing long established in addiction recovery services (White, 1998).[3] In the last decade, examples of both consumer staffing and consumer-run programs have proliferated. At Housing Works, a minority-run agency that provides housing and services for New Yorkers who are homeless and living with HIV/AIDS, 25 percent of employees are people who are or were program clients. They work in diverse roles in the agency's housing and service programs and in its thrift shops, bookstore, and catering business (Housing Works, 2005). National Mental Health America (NMHA), a collaborative advocacy and service organization for people with mental illness that includes consumers throughout its staff and administrative structure, identifies 10 homeless assistance programs operated by local MHA affiliates across the country (NMHA, 2006). Solutions at Work, an agency in Cambridge, Massachusetts, led and run by people who are or were homeless, helps people transition out of

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[3]   Treatment services for alcohol and drug addiction have for decades relied on a large mutual support component represented in 12-step groups such as Alcoholics Anonymous and Narcotics Anonymous that often serve as an alternative, sometimes as an adjunct, to professionally delivered treatment (White 1998). In many programs, peer support is an integral part of addiction treatment for people who have experienced homelessness (Galanter 2000).

homelessness by providing tangible resources, including paid transitional employment, clothing, furniture, moving services, automobiles, computers, and leadership training (Solutions at Work, 2006).

The Consumer Involvement Workgroup, established by state-level administrators of SAMHSA's Projects for Assistance in Transition from Homelessness (PATH) program, recently surveyed the employment of mental health consumers with homelessness experience in 378 PATH programs in 41 states. One-quarter of the programs employed at least one consumer, mainly to deliver outreach (85 percent), referral (62 percent) or case management (58 percent) services. About two-thirds of these were mental health consumers who had experienced homelessness (PATH Consumer Involvement Work Group, 2006). We review below both studies of peer employment in homeless services and mental health programs and the growing body of research on service programs operated by mental health consumers.

Consumers as staff: Peer outreach/case management. A decade ago, Glasser presented a compelling case for the special abilities of consumers to engage people experiencing homelessness in services (Glasser, 1999). Drawing on work by Van Tosh (1993) and others, she summarized several aspects of consumers' experiences that facilitate effective outreach, including knowledge of streets and service systems, flexibility and openness to new approaches, understanding of and responsiveness to client preferences and needs, empathy and rapport with people who are homeless, and positive role modeling. Consumer staffing of homeless services has mainly been studied in outreach and case management programs. In a study of peer engagement of persons who are homeless, Fisk and Frey (2002) describe an 18-month supported socialization project that employed two peer outreach workers eight hours a week. After three months of training and orientation, peers were assigned to join existing staff on weekly outreach runs. The peer workers conducted outreach with 50 individuals who were homeless, working closely with 6 who had been previously unresponsive. They developed relationships with all 6 and successfully engaged 4 in mental health treatment and in moving to shelters or housing. These findings on engagement were extended in a larger experimental study comparing peer-based versus usual case management for people with mental illness, which demonstrated the effectiveness of peer engagement early in treatment. At six-month follow-up, participants perceived higher positive regard, understanding and acceptance from peer providers, and initially unengaged clients had increased contacts with peer case managers and decreased contacts with non-peer case managers. Positive regard, understanding, and acceptance at six months predicted motivation and involvement in psychiatric, alcohol, and drug treatment at 12 months (Sells et al., 2006).

The research literature also includes studies that address consumer integration into assertive community treatment (ACT) teams—the personal benefits and structural difficulties consumer staff experience and the effects of consumer staffing on housing and other outcomes. A study of consumer case managers in an ACT program for persons who are homeless identified challenges to consumer staff integration into conventional ACT teams and strategies to address those issues (Fisk et al., 2000). (See Exhibit 7.) This study extends findings on peer staffing in non-homeless mental health programs (Kirsch, 2000; Mowbray, Moxley, & Collins, 1998; White et al., 2003), documenting both individual benefits for peer staff (income, skills, safe and positive work situations) and stresses in the workplace environment (inadequate preparation and support, concerns about boundary issues, superficial supervision, and stigma).

Chinman and colleagues studied outcomes of 987 individuals at six ACCESS program sites employing consumer case managers (Chinman et al., 2000). Baseline data showed that people served at these sites had more difficulties (psychotic symptoms, depression, drug use, homelessness) than those at 12 other

Exhibit 7

Consumer Case Managers in Homeless Outreach Programs ACT Teams

Challenges	Strategies	Benefits
Consumer status can evoke discrimination	Educate and train staff	Enrich team functioning and undermine stereotypes
Peer staff face decisions about boundary-breaking service interactions	Ensure adequate individual supervision for peer staff	Challenge team members to reduce client-staff distances and improve services
Workplace discrimination occurs in staff interactions and in pay differentials	Clarify workplace issues requiring reasonable accommodations	

ACCESS sites. However, within consumer-staffed sites, persons with consumer case managers did not differ from those with non-consumer case managers in clinical, social functioning, or occupational outcomes; in movement to permanent housing; or in therapeutic alliance with a case manager. The findings indicate consumer case managers are as effective as non-consumer case managers, even at sites serving persons experiencing greater difficulties. The study extends evidence on effectiveness of peer support and case management in non-homeless assistance programs (Felton et al., 1995; O'Donnell et al., 1999; Herinckx et al., 1997; Solomon & Draine, 2001), adding support for consumer case management as an effective approach for addressing homelessness.[4]

Emerging practice: Certified Peer Specialists (CPS). Stable funding for peer employment has proven difficult to sustain (Glasser, 1999; Mowbray, Moxley, & Collins, 1998). Georgia's Certified Peer Specialist program offers an innovative resolution to this issue. The program combines consumer-provided services, consumer advocacy, and consumer influence on policy. It is open only to current or former recipients of mental health services "who openly identify as consumers and have had advocacy or advisory experience in addition to demonstrated effort at self-directed mental health recovery" (Sabin & Daniels, 2003, p. 497). Certification requires two week-long training modules, followed by oral and written examinations. CPSs act as change agents to model and support consumers in regaining control over their lives and their recovery through specific supportive activities (e.g., developing a wellness plan, supporting vocational choices, providing help utilizing community social support). CPS services are billable to Medicaid, and Georgia requires ACT teams, community support teams, and adult peer support programs to include CPS as a condition of reimbursement, providing unusual institutional support for recovery-focused services and peer employment.

Hawaii, South Carolina, Massachusetts, and Pennsylvania are among the states that have developed certification programs. Arizona, Iowa, Michigan, Washington, and Washington, D.C., have joined Georgia in providing Medicaid reimbursement for CPS services (National Mental Health Association of Southeastern Pennsylvania, 2006). The CPS approach has face validity (Sabin & Daniels, 2003), but as yet, research has not established the effectiveness of the selection and training aspects of the program, its impact on those who become certified, or its impact on ACT and other service models in which CPS staff

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4   RCTs are needed to make a more definitive case for effectiveness by ruling out the possibility that unmeasured characteristics related to case manager assignment might account for the equivalent outcomes.

are used. Accumulating evidence for consumer case managers in homeless assistance programs (Chinman et al., 2000) and evidence for effectiveness of the CPS model could significantly broaden the evidence-based options for consumer involvement in homeless service delivery.

Parallel efforts are emerging to train and deploy peer specialists in service programs for people with co-occurring disorders (Center for Substance Abuse Treatment, 2004) and to add addiction recovery coaches to the mutual support groups and professional treatment programs that currently dominate addiction services (White, 2004). Both emphasize inclusive, culturally sensitive approaches as well as "diverse pathways and styles of recovery, a preference for voluntary versus coerced participation, a focus on wellness/wellbriety/global health versus a singular focus on abstinence" (White, 2004, p. 6) There is no research on whether or how these interventions affect homelessness.

Organizational advantages of employing consumer staff. Effectively employing consumers in agencies supportive of consumer integration can be beneficial to both the agency as a whole and specific agency services. Consumer staff can bring expertise about system use and recovery to increase the overall balance of staff areas of competence. In addition, working alongside consumers as colleagues can open agency staff and administrators' eyes to the real possibilities of recovery for others using their services. As noted in the PATH Consumer Involvement Workgroup report (2006), "Successful integration of consumer practitioners into PATH programs sends an important message to traditional staff and to outside agencies and systems that individuals with serious mental illness who experience homelessness can and do recover, and they can play an important role in the delivery of mental health services to their peers."

Consumer-operated services. There are several descriptive accounts of consumer-run programs offering advocacy, housing, peer support, and drop-in services for people experiencing homelessness, but outcomes research on consumer-operated programs has rarely focused on homelessness. However, the processes underlying peer support—variously conceptualized as social support, experiential knowledge, modeling of confidence and coping behavior, and the "helper-therapy principle" (Solomon, 2004) or as a combination of emancipatory and caring functions (Campbell, 2006a)—address the kinds of disempowering circumstances that homelessness imposes.

Descriptive accounts: Diverse models and common principles. In the last decade researchers have studied diverse consumer-operated program models: consumer-run ACT teams and other forms of case management (Paulson et al., 1999; Herinckx et al., 1997; Solomon & Draine, 2001); employment programs (Miller & Miller, 1997); an array of drop-in and socialization services; advocacy and educational programs; and peer support services (Yanos, Primavera, & Knight, 2001; Nelson et al., 2006; Ochocka et al., 2006; Clay, 2006; Segal & Silverman, 2002; Nelson, Hall, & Walsh-Bowers, 1998). The best-documented consumer-operated programs are those providing peer support services to people with mental illness as either an adjunct or alternative to professional treatment services. SAMHSA's Center for Mental Health Services (CMHS) recently coordinated a national survey that identified 7,467 such groups and organizations, including 3,315 mutual support groups that reported 41,363 attendees at their last meetings; 3,019 self-help organizations with 1,005,400 members; and 1,133 consumer-operated services that serve 534,551 members/clients annually. While only 12 percent of mutual support groups reported that they helped participants with housing issues, 48 percent of self-help organizations and 58 percent of consumer-operated services did so (Goldstrom et al., 2006).

Given variations in program modalities and services, several schemas have been developed to identify core or defining features of consumer-operated program approaches. Glasser's (1999) report emphasized client-defined needs; voluntary participation; choice in degree of participation and program components; clients helping each other; service recipients' responsibility for overall program direction and financial and policy decisions; and program responsibility to clients—not to relatives, other providers, or funders (Mowbray, Wellwood, & Chamberlain, 1988). Solomon's research review proposed five service characteristics as defining ingredients of consumer-run services: mutual benefit, experiential learning, natural social support, voluntary services, and consumer control of services, though only the first three have been tested in rigorous outcome studies (Solomon, 2004). Campbell (2006a, pp. 38-39) identifies 10 emancipatory functions and 10 caring functions rooted in the philosophy of peer-run support programs that distinguish them from professional mental health services. (See Exhibit 8.) SAMHSA's Consumer Operated Service Programs (COSP) study defined eight "core principles" within five domains (see Exhibit 9) that distinguish COSP from usual treatment, and used them in outcome analyses reported below (Campbell, 2006b; Clay, 2006; Johnsen, Teague, & McDonel Herr, 2006). Particulars differ, but the themes of support, respect, choice, self-determination, and personal agency recur in the various accounts of distinctive features of consumer-operated services.

Exhibit 8

Distinguishing Peer-Run Support Programs from Traditional Mental Health Services

Emancipatory Functions	Caring Functions
• Autonomy	• Empathic support
• Equality	• Non-pressured and non-judgmental support
• Advocacy	
• Empowerment	• Holistic approach
• Self-definition of needs	• Responsiveness to diversity
• Role modeling	• Group support
• Information dissemination	• Mutual respect
• Inclusion in research and policy-making	• Experiential knowledge
	• Recovery orientation and hope
• Consciousness raising	• Personal growth in helping others
• Taking responsibility	• Safety in crisis

Exhibit 9

Core Principles Identified by SAMHSA's Consumer Operated Service Programs

Structure

• Consumer operated

Environment

• Safe from coercion

Belief system

• Peer principle
• Helper's principle
• Empowerment

Support

• Peer support

Education and advocacy

• Problem-solving strategies
• Self-advocacy

A study comparing consumer-operated case management teams with non-consumer teams in the same consumer-run agency used staff activity logs, focus groups, and participant observation to describe related differences in the "work culture" of the two kinds of teams. Consumer teams emphasized flexible boundaries, less often asserted authority to leverage client compliance, valued "being there" with clients over schedule and task-focused interactions, and less often described their work with clients as burdensome (Paulson et al., 1999)*.*

Effectiveness of consumer-operated service programs: Outcome studies. Early studies established the feasibility of consumers of mental health services providing support and services for other consumers (Mowbray, Wellwood, & Chamberlain, 1988; Segal, Silverman, & Temkin, 1995). Recent review articles summarize several decades of outcomes research on peer support and consumer-operated programs for people with mental illness showing that participants have equivalent or better outcomes across several domains—including psychiatric

symptoms, rates and length of hospitalization, and social integration (Davidson et al., 1999; Davidson et al., 2006; Solomon & Draine, 2001; Campbell, 2006a; Solomon, 2004; Nelson et al., 2006).[5] Effects on homelessness have rarely been examined.

Two recent quasi-experimental studies support consumer-run programs as a promising practice. One study showed that participants in consumer-run services had better social functioning than those involved only in traditional mental health services; psychological variables were significantly associated with social functioning; and the relationship between involvement in consumer-run services and social functioning was partly mediated by the use of more problem-centered coping strategies (Yanos, Primavera, & Knight, 2001). The other found that active participants in Consumer Survivor Initiatives in Ontario, Canada, had less hospitalization, better social support, and equivalent clinical outcomes over the 18-month follow-up, compared to those who were inactive (Nelson et al., 2006).

Three experimental studies have examined consumer-run case management programs. An early study that randomly assigned participants to usual mental health treatment versus consumer-run vocational support in addition to professional vocational services found better vocational outcomes (employment, income, vocational status) for those receiving consumer support, but the design precludes sorting out the effects of peer supports from the professional vocational services (Kaufman, Schulberg, & Schooler, 1994). Solomon and Draine (1995) compared consumer versus non-consumer ACT teams and found consumer team members more often delivered face-to-face services in non-office settings; symptoms, clinical and social outcomes after two years were equivalent. A study that randomly assigned participants to consumer-run ACT teams, non-consumer ACT, or usual care found no differences in behavioral symptoms or clinical or social outcomes—including homelessness (Herinckx et al., 1997; Clarke et al., 2000).

SAMHSA's Consumer Operated Service Programs multisite research initiative. In 1998, SAMHSA launched the largest study of consumer-run services ever undertaken (*N*=1,827), designed to assess effectiveness of COSPs as adjuncts to traditional mental health services. Study participants were randomly assigned to traditional mental health services or traditional mental health services *plus* consumer-operated services and followed over 12 months using a common interview protocol and multiple outcome measures in existential, clinical, and objective domains. Consumers were involved at all levels of the project.

Three major categories of programs were included in the study: education/advocacy, drop-in, and peer support services. All met COSP criteria as administratively controlled and operated by mental health consumers, with an emphasis on self-help as the operational approach, and all were guided by principles and practices based on emancipatory and caring functions (Campbell, 2006a). To operationalize "consumer-operated services," address program diversity, and specify contrasts between the experimental

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[5]   Studies of self-help groups show those who attend have symptom outcomes similar to or better than non-attendees (Kaufman, Schulberg, & Schooler, 1994; Powell et al., 2001; Moos et al., 2001). Greater commitment to the group is associated with symptom improvements (Galanter, 1988; Raiff, 1984). Participants have the same or lower rates of hospitalization (Kurtz, 1988; Galanter, 1988; Kennedy, 1989; Rappoport, 1993; Edmondson, Bedell, & Gordon, 1984; Trainor et al., 1997; Trainor & Tremblay, 1992), and shorter duration of stay (Solomon & Draine, 2001). They are more socially integrated—as indexed by larger social networks (Rappaport et al., 1985; Roberts & Rappaport 1989), more pursuit of work and education (Kaufman, 1995), more involvement in formal social roles (Zimmerman et al., 1991); and they have better social functioning (Carpinello, Knight, & Janis, 1991; Galanter, 1998; Kaufman, 1995; Markowitz, DeMasi, & Carpinello, 1996).

and control conditions, the research team identified and defined COSP common ingredients, and developed feasible indicators with specified performance anchors. Outcome analysis to date has focused on "well-being," a construct developed from the validated scales measuring existential domains of experience—recovery, empowerment, quality of life, social inclusion and acceptance, meaning of life, hope. Analyses showed greater program use was significantly associated with greater well-being, and a strong relationship between increase in well-being and recovery-oriented program features.[6] Findings held up across the three COSP models (Teague et al., 2006; Campbell, 2006b).

Exhibit 10

Findings of Consumer/Survivor Initiatives in Ontario

Initiatives engaged in:

- Public education
- Political advocacy
- Community planning and collaboration
- Action research devoted to community planning activities

Changes in policy and practice, including:

- Use of peer support specialists and consumer councils in traditional mental health programs
- Increased referrals to Consumer/Survivor programs
- Increases in supportive housing
- Reinstatement of transportation subsidy
- Reversal of funding cuts for mental health services

The COSP initiative was not designed as a study of consumers who are homeless, though baseline data show that over 50 percent of study participants had previous homeless experiences, even more in the drop-in programs (Campbell, 2004). Current analyses are examining housing outcomes,[7] but since most participants, including those who had been homeless, had stable residences when they entered the study, investigators do not expect to find significant effects. The role COSPs can play in addressing homelessness remains to be established.

System impacts of consumer-operated programs. Although most consumer-operated programs provide direct services, some seek a broader systemic impact. One program, Staff Supporting Skills for Self Help, aimed to improve the competencies of mental health providers through manualized programs of education, clinician-client dialogues, technical assistance, and introducing self-help into clinical settings. A quasi-experimental study of the intervention found improved clinician competencies, increases in recovery-oriented services, and growing use of self-help in the experimental sites, though local community events appeared to have countered expected effects on stigma (Young et al., 2005).

Janzen and colleagues used mixed methods to study the system-level impacts of four consumer-run organizations referred to as Consumer/Survivor Initiatives (CSIs) in Ontario. Using staff activity logs,

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[6] Initial analyses showed improvement in well-being over time for both experimental and control groups, with significantly greater improvement in a subset of COSP sites, but failed to confirm the overall hypothesis. However, these analyses also showed that some participants "crossed over" from COSP to usual services during the course of the study. Because conventional "intent-to-treat analysis," which makes comparisons based on original group assignment, regardless of whether those randomly assigned to experimental and control groups actually participated in their assigned programs, may understate effects of program involvement, subsequent analyses employed an "as treated" approach. These analyses compared groups that actually participated in experimental or control services. "Propensity scoring" was used to divide the sample into homogeneous strata and compare outcomes for experimental and control participants within strata to avoid mistaking outcome differences that may occur because experimental and control programs attract different kinds of participants for those that result from program differences.

[7] Most consumers remained stably housed throughout the study, limiting the likelihood of showing significant effects of COSP on homelessness (Jean Campbell, personal communication, 8/8/06; Gregory Teague, personal communication, 8/8/06). Thus whether COSPs effectively address homelessness may remain an open question.

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interviews, and focus groups, they identified activities and participant-assessed impacts. (See Exhibit 10.) Since this activity was collaborative, it is not possible to isolate the contribution of the CSI to most of these achievements, though interviews with non-CSI participants support participants' perspectives on system-level impacts (Janzen et al., 2006).

Our review of consumer involvement in service delivery finds accumulating examples of consumer staffing in programs that address housing and homelessness. Descriptive studies show that peer staff experience both personal benefits and structural difficulties. Quasi-experimental and experimental studies comparing consumer outreach/case management staff versus non-consumer staff find equivalent clinical and social outcomes among service recipients, lending support to the hiring of consumers in service delivery programs as a promising practice. Despite the long history of some consumer-operated programs that focus on housing and services for people who are homeless, there is virtually no research assessing the effects of these programs on homelessness. However, a growing body of work describes key principles of programs operated by consumers of mental health services, and the recently completed SAMHSA study of COSPs has reported improvements in well-being (a composite of recovery-related measures) associated with key principles of consumer-operated service delivery. Further research will be needed to determine whether such programs effectively address homelessness.

Barriers to and Strategies for Consumer Integration

Many barriers to meaningful consumer participation reflect the exclusionary processes and practices that produce homelessness; concentrate its effects on people already disadvantaged by racism, poverty, and disability; and undermine efforts to end homelessness. Homelessness research typically focuses on individual correlates and risk factors, but a large multidisciplinary literature reminds us of the social machinery that creates differential life chances for individuals and the social conditions that unevenly distribute the "risk of risk" (Link & Phelan, 1995). Various concepts—structural violence in public health (Farmer, 2004); structural racism in analyses of race and poverty (Hartman, 2001; Stone, 2006; Wilson, 1996); capability deprivation in developmental economics (Sen, 1999)—have been used to summarize processes that compound historical disadvantages and reproduce them in the structure of contemporary labor and housing markets, educational opportunities, safe environments, and access to health care. Consumer self-determination and integration into research, policy, planning, and service delivery will require acknowledging and addressing the range of constraints that marginalize the voices of those who have experienced homelessness.

Race, ethnicity, and poverty. The overrepresentation of people of color, and particularly African Americans, among those who experience homelessness is widely documented but rarely discussed in reports on homelessness. In one of the few analyses of this phenomenon, Hopper (2003) describes the market losses in affordable housing and decent work, mounting strains on extended families, growth of the drug trade, and continued failures of community-based mental health services that made homelessness among African Americans an all but foregone conclusion. Citing Ellison (1980), he notes that the "invisibility" of black homelessness is not an accident but the product of a determined refusal to see (Hopper, 2003, p. 171).

Earlier work on homelessness described a "Latino paradox" (Gonzalez Baker, 1996), noting low rates of homelessness despite high rates of poverty, poor housing conditions, and housing discrimination and suggesting that community networks were able to absorb those who would otherwise enter shelters. In many locales, this has changed. Moreover, Latinos who are immigrants encounter special barriers related

to accessing available services—including language, but also increasingly virulent discrimination and legal exclusions initiated under welfare reform legislation that deny eligibility for a variety of federal benefits (TANF, SSI) even to many documented immigrants (Broder, 2007).

Although the intertwined impacts of race, ethnicity, and poverty are not prominent in written accounts of consumer experiences in research, policy, and planning, individual members of consumer advisory groups confirm that these issues are discussed *within* consumer panels and in other interactions among consumers of color. Efforts to introduce these insights in research or policy discussions, however, are viewed as divisive and evoke denials from non-consumer professionals, effectively denying voice to consumers of color who want to bring deeply felt experiences into policy or research discussions. Until the structural nature of racial exclusion, reflected in excess disability and mortality, educational disadvantage, housing discrimination, labor market exclusions, and the stigmatizing assumptions that accompany it are recognized, progress in the effort to address homelessness will be limited.

Poverty has been more readily recognized as a barrier to consumer participation, and strategies to offset its immediate impact have been developed. The Homeless Families Program's consumer panel (CP) distributed prepaid phone cards to ensure that members attending steering committee meetings would be able to stay in touch with children's babysitters, and found that financial support for travel, childcare, per diems and other expenses were essential to sustain consumer participation (McMullin et al., 2006).

Stigma and discrimination. Reports identify stigma and discrimination as recurring features in homeless service settings, though they do not typically consider how homelessness, mental illness, race, substance addictions, HIV, and poverty are causative factors of stigma in these venues.

Link and Phelan (2001) view stigma as a set of interrelated processes—labeling, stereotyping, separation, status loss, and discrimination—that co-occur in a context of unequal power. They identify three broad categories of stigmatizing mechanisms that operate at individual, interpersonal, and structural levels. This conceptualization implies that effectively combating stigma and discrimination requires addressing not only labeling and stereotyping (interpersonal stigma), and the negative views adopted by stigmatized persons (self-stigmatizing perceptions) but also the discrimination perpetuated by disempowering institutional arrangements (structural stigma). Consumer accounts of personal experiences in homelessness research, policy, and service contexts provide examples of mechanisms that operate and diverse strategies for countering them (McMullin et al., 2006; Mockus et al., 2005).

Stigma and discrimination are particularly problematic for consumer staff who experience them both in the organizations that hire them and in their interactions with contracted provider agencies. (PATH Consumer Involvement Workgroup, 2006). Fisk and colleagues (2000) highlight the importance of recognizing and responding to both subtle and overt discrimination.

Disclosure of consumer status. The decision of employees to disclose their consumer status to employers, other agency staff, or clients is sometimes a personal decision, but at times it may be required as a condition of employment. Depending on the work situation, disclosure of consumer status can highlight an agency's commitment to the recovery model, which includes hiring consumers as staff. Disclosure of consumer status to an individual using agency services may stimulate hope of recovery on the part of the client, or it may aid both the consumer staff's and the client's recovery process. (PATH Consumer Involvement Workgroup, 2006)

Without clear administrative support of consumers as staff and the education of all staff about the value of including consumers on staff, disclosure can lead to difficulties in working conditions. Fisk and colleagues (2000) note that discrimination is likely to occur immediately after consumers make disclosures. In addition to education of all staff, they recommend individual supervision, which allows an opportunity to discuss workplace difficulties; provision of support as needed; and peer support groups, which give consumer staff opportunities to discuss challenges and successes, observe role models, build solidarity, and decrease feelings of isolation on the job.

Interpersonal stigma (harboring low expectations, negative stereotyping) has been both described and challenged by consumers across all domains of research, policy, and planning. In qualitative interviews conducted by a Homeless Families Program CP member, participants described hostile, disrespectful, and humiliating treatment when seeking help from shelter and social service staff. (Stainbrook, 2004, p. 23; Deming, 2002).

Consumer panel members on SAMHSA's research initiative on Women with Co-Occurring Disorders and Violence, who referred to themselves as consumer/survivor/recovering (C/S/R) women, wrote of their initial experiences at the initiative's Steering Committee meetings:

> It was confusing and disturbing to be identified with a label and to be asked to speak as a C/S/R woman. In talking about that early experience, one woman said it was like being "a performing monkey," another said she felt like "a sham," and others used words like "marginalized," "tokenism," "invisible," "discounted," and "not heard." …True discourse developed slowly over time. Other Steering Committee participants seemed to need time to develop better "hearing" so that C/S/R women were not discounted because of preconceived beliefs about who they were (Mockus et al., 2005, p. 522).

The women from this project collectively pressed for a variety of supports (including a scheduled place and time to meet together outside the formal steering committee sessions; a training academy in research methods; practical support—financial, child care—for attendance at meetings) that allowed them to find their individual and collective voice. As researchers became more willing to listen, C/S/R women's influence on the project grew.

Fisk and colleagues (2000) describe the subtly stigmatizing interactions that consumer staff experienced in integrated case management teams. They emphasize the importance of educational and training programs for non-consumer staff, individual supervision for consumer staff, and management intervention to create a more positive work environment.

For many people experiencing homelessness, stigma and discrimination are perpetuated by a mental health system that "considers every difficulty people with psychiatric problems experience as an indication of mental illness requiring professional expertise," so that even requests for practical assistance with a job or a place to live are handled within the context of disability (Campbell, 2006a, p. 38). Consumers recount experiences in research, policy, and planning settings, in which the recovery movement has served as both resource and strategy in challenging preconceived notions about the abilities of consumers who have experienced mental illness, recovery from addiction, and homelessness (McMullin, 2006; Clay, 2006).

Self-stigmatizing perceptions (lack of confidence, feeling worthless) arising from repeated experiences of powerlessness and discrimination may also inhibit consumer involvement in research, policy, and service delivery. Shih (2004) emphasizes resiliency and strategies individuals use to overcome stigma as well as distinguishing coping approaches, which may be psychologically draining, from empowering processes that produce resiliency and overcome adversity. In one report, families that became involved in organizing activities demonstrated that "active participation of homeless families reduces severe isolation, guilt, and shame and can provide critical support" (Better Homes Fund, 2001, p. 13). Tripp's presentations on opportunities for consumer involvement in HMIS also emphasize that the experience of participating, learning, and being effective evokes personal growth and improved self-image (Tripp, 2005). Some accounts suggest that individuals who are spurred to action to address the injustice of stigma at the level of individual identity often adopt an empowerment approach that leads to engagement in efforts aimed at removing stigma at the collective level (Corrigan & Watson, 2002).

Structural stigma (barriers to participation due to exclusionary social structures, power differentials, and poverty) can occur even when not directly linked to the negative stereotypes often understood to define stigma. The PATH Consumer Involvement Workgroup (2006) noted that eliminating pay differentials is only one aspect of treating staff equally and encouraged agencies to be sensitive to and address differences between consumer and non-consumer staff. The Homeless Families Program CP resolved issues around exclusionary practices, such as using credit cards to hold plane and hotel reservations, communicating by email, and scheduling conference calls and meetings in distant cities during the workday, which are so embedded in professional research culture that their effects on consumers often were ignored and unacknowledged by researchers. The CP coordinator, steering committee, and individual sites implemented CP recommendations to facilitate participation by CP members, including financial support, aid with travel logistics, and advance distribution of hard copies of written material (McMullin et al., 2006). As long as the larger inequities remain, such efforts are needed to offset their exclusionary effects.

Mainstream employment: Barriers and labor force development strategies. Research on employment of consumers with mental health and other disabilities has documented their strong interest in work but low rates of employment. A New Freedom Commission Subcommittee on Employment and Income Support reported that despite initiatives to reduce barriers to work, ineffective vocational services, workplace discrimination, and work disincentives perpetuate low employment rates of people with mental health disabilities (New Freedom Commission Subcommittee on Employment, 2003). Studies of peer employment show that the Americans with Disabilities Act has not had hoped-for effects on workplace discrimination (Fisk et al., 2000; Kirsch, 2000), and a qualitative study of consumer staff in a mental health agency describes mixed consequences of invoking ADA's reasonable accommodation provisions (Francis, Colson, & Mizzi, 2002). The Ticket to Work program, intended to enhance vocational skills, has served only a fraction of those in need, and "creaming," that is, serving only those who are easiest to serve, may result in limited access for people with mental illness (Employment Subcommittee, 2003). Few states have implemented a Medicaid Buy-In initiative to allow working consumers ongoing access to health insurance (Employment Subcommittee, 2003; Silverstein & Jensen, 2004).

Financing of peer staff positions through time-limited demonstration grants has also inhibited consumer employment (Mowbray, Moxley, & Collins, 1998; Center for Substance Abuse Treatment, 2004). Georgia's experiment with employing certified peer specialists, who have a mandated role in several Medicaid-reimbursable services, is a notable step in enhancing peer employment. While many states have

implemented training and certification programs, Georgia's reimbursement strategy has been less widely adopted, although there is growing support for increased use of Medicaid-reimbursable services. This is so despite recommendations that peer support services be integrated into the continuum of community care and that public and private funding mechanisms be made sufficiently flexible to allow access to these services, for example, through a carve-out from federal Community Mental Health Block Grant funding to support both integration of peer support services within the continuum of community care and procedures to encourage use of billable peer services under the Medicaid Rehabilitation Option (Employment Subcommittee, 2003; Center for Substance Abuse Treatment, 2004). Opposition to hiring certified peer specialists remains a reality in many organizations.

Funding issues. Funding issues pose additional barriers. Although early studies showed cost savings associated with peer support programs, in some cases this reflected use of peer volunteers or lower rates of pay for peer staff (Solomon & Draine, 2001). Consumers and researchers have criticized use of peer staffing to reduce personnel costs, emphasizing pay parity as a basic principle of consumer staffing, and noting that its benefits come from the value added to program services (Mowbray, Moxley, & Collins, 1998). This is especially critical at a time when cost-effectiveness is a central selling point in any effort to implement innovative services.

SAMHSA's recent research initiatives underscore a need to fund the supports that ensure peer integration through all of a project's phases and levels. This entails allocating resources for transportation and child care, consulting stipends, per diem expenses, and meetings/conference calls among consumers to ensure adequate discussion to clarify issues and formulate responses; contracts with consultants to provide assistance with group process, training in research methods, and advice on public presentations; and mailing expenses to distribute materials that researchers circulate by email (Campbell, 2006b; McMullin et al., 2006; Mockus, 2005). Overall amounts are not large, and a decision to earmark funds to enable consumers to participate as research, policy, and service delivery partners marks a move from token involvement toward consumer integration.

Consumer Self-Determination in Housing and Services

Service and Housing Priorities and Preferences

Since the early 1990s, research and other literature have consistently and unambiguously documented discrepancies between provider and consumer perspectives on how to prioritize housing and services, and on the kind of housing needed. A comprehensive array of outreach, transitional, and permanent housing programs is now well established at city and state levels through provider participation in the annual continuum of care application to HUD, which funds and shapes the direction of local services. While this broad offering of services provides some people who are homeless with options for exits from homelessness, point of entry into housing is usually not determined by consumers themselves, but by service providers. Housing providers often worry about the potential for disruptive and dangerous behavior, as well as the possibility of recurring homelessness, if people with mental illness and addiction problems are given independent housing before demonstrating that they are ready for it. Similarly, clinician beliefs in the limited ability of persons with mental illness to maintain independent housing can restrict the paths that consumers take into housing. Indeed, when surveyed about housing needs, providers more often recommend staffed settings with on-site treatment or supports (Bebout & Harris, 1992; Goering, Paduchak, & Durham, 1990; Goldfinger & Schutt, 1996). Therefore, in most programs across the country, approaches to housing and services for people who are homeless have reflected provider

perspectives, emphasizing outreach and shelter as first responses. They offer emergency supplies (food, clothing), support, and referrals to transitional settings such as drop-in centers and safe havens that offer support and treatment services to help consumers become "housing ready." In contrast, researchers and advocates studying consumer preferences in housing and consumers themselves all report that consumers who are homeless want housing *first*— housing on their own terms: independent, integrated into the community, with the support services an individual chooses available off site but not required (Carling, 1993; Howie the Harp, 1993; Tanzman, 1993).

While there are numerous examples of very successful "housing readiness" programs, the visibility of a highly vulnerable group of consumers who have been homeless for years has recently prompted researchers and other observers to focus attention on chronic homelessness and to join consumers in challenging the treatment-as-usual service approaches. Kuhn and Culhane (1998) found that among all who stay in shelters over the course of a year, a small group (about 10 percent) with long and repeated stays use half of all system resources (days of shelter use). Their work suggests that extensive engagement and contact with outreach, shelter, transitional housing, and clinical services have been very costly but ineffective for this group. Gladwell's (2006) poignant portrait of "Million Dollar Murray" highlights the experience of thousands of people who are chronically homeless. Gladwell provides a litany of well-intentioned but failed service efforts by outreach workers, police, detox and psychiatric emergency room staff, and many others who tried to help Murray leave the streets of downtown Reno, Nevada. Murray wanted a place of his own but no one believed that he was "ready" for it (in fact, he did well when he once briefly had a place, but without support services he soon lost it and there were no more chances after that). A tally of the cost of providing 12 years of failed services to Murray gave Gladwell a nickname for his anti-hero, and highlighted the need for new strategies.

In the last decade, new approaches emphasizing consumer choice and recovery (Deegan, 1988; Mead & Copeland, 2000; Ridgway & Press, 2004) have challenged traditional models requiring treatment and sobriety as preconditions for housing. What is shared by well-documented, consumer-driven approaches, such as wellness recovery action plans (WRAP) (Copeland, 1997), motivational interviewing (Miller & Rollnick, 2003), shared decision making (Deegan, 2007), and housing first (Tsemberis, 1999), is that programs must allow consumers to be equal partners in choosing providers and determining the type and sequence of services they receive, including the right to refuse services altogether (New Freedom Commission on Mental Health, 2003).

Approaches to housing and services cannot be neatly dichotomized between treatment and sobriety first providers on the one hand and housing first providers on the other. Although treatment and sobriety are common preconditions for accessing permanent housing, some homeless assistance programs make participation in treatment and support services optional once individuals meet initial treatment requirements for admission. Since the 1980s, community development activists and homeless advocates, who have viewed an expanded supply of permanent affordable housing as essential to any efforts to end homelessness, have collaborated to reclaim or replace disappearing housing stock by creating integrated housing developments (Hopper & Barrow, 2003).[8] These programs offer SRO accommodations or

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[8] We use the term "integrated housing development," to refer to a type of supportive housing that accommodates diverse housing-needy individuals—among whom those with mental illness are not the majority—in single apartment or SRO units. Services are available on site but from a provider separate from the housing manager, and tenure is not contingent on sobriety or service involvement (Hopper & Barrow 2003).

efficiency apartments for diverse groups with housing needs, including people with mental illness, people living with HIV/AIDS, and other low-income members of local communities. Subsidies ensure affordability; standard leases ensure tenancy rights; and nonprofit service agencies make optional support services available on site, usually in inconspicuous locations, which tenants may use or not, as they wish. However, integrated housing development programs, like most congregate housing settings, often face challenges, juggling as they do to support individual tenants through periods of symptom or substance use relapse, maintain a viable environment for the tenant community as a whole, and keep admission requirements reasonable (Barrow, Soto Rodriguez, & Cordova, 2004; Hopper & Barrow, 2003).

Housing First: A Paradigm Shift in Homeless Services

The inclusion of consumer voices in the planning and implementation of housing and services has fostered a paradigm shift in homelessness interventions and moved outreach, engagement, treatment, and housing services to be more in line with consumer preferences. In the last decade, housing first, developed in partnership with consumers, has emerged as a well-documented practice that effectively provides permanent housing that is not contingent on prior services or "readiness" criteria. The housing first approach was pioneered by Pathways to Housing. By offering consumers an apartment of their own as a direct exit from homelessness, "Pathways fused several programmatic steps—outreach, engagement, and housing—into a single powerful and desirable invitation" (Tsemberis et al., 2003, p. 310). This approach is consistent with consumer priorities for an independent apartment of their own without requirements for psychiatric treatment or sobriety as a condition for housing entry or retention.

The pathways to housing model. The pathways to housing model emerged from an ongoing dialog among consumers, staff, and researchers (Shern et al., 2000; Lovell & Cohen, 1998; Tsemberis et al., 2003) who had developed an outreach and drop-in center program as an NIMH research demonstration project. An ethos of respect for consumers and their wishes was fostered by training staff in consumer-centric clinical approaches such as psychiatric rehabilitation (Anthony et al., 2002). In addition, several staff members were consumers themselves, and consumers shared responsibility for policy and program decisions. Howie the Harp, an early consultant, brought to the program a commitment to social justice and revolutionary fervor to change the mental health system (Tsemberis & Asmussen, 1999; Tsemberis & Eisenberg, 2000; Tsemberis et al., 2003).

In the drop-in center, neither status nor salary distinguished consumer staff from non-consumer staff, an approach that also blurred boundaries between staff and participants and fostered collaboration on the critical problem of access to housing. Staff and consumers witnessed how existing housing providers used the need for housing to leverage consumer acquiescence to unwanted treatment and abstinence requirements (Allen, 1996). After repeated failures to secure housing for consumers, the group began a trial and error process to design a housing program that would be desirable to consumers and manageable to staff. They determined that the scattered-site supported housing model met consumers' requirements for normal housing, tenancy rights, privacy, and an affordable rent contribution (30 percent). Consumers and staff collaboratively worked out operational details, occupancy policies, and program and consumer fiscal responsibilities, including a program account that required both staff and consumer signatures for checks to be cashed.

This collaborative plan evolved into the pathways to housing model, which focuses on ending homelessness by offering permanent, independent housing and comprehensive, consumer-driven supports without contingencies for treatment or sobriety. The pathways model, now called housing first, prompted

several programs and agencies around the country to adopt this approach in their efforts to end chronic homelessness. However, the Pathways program and the numerous replication sites are not the only programs that are described as housing first. Locke and colleagues (2007) identify several variations of housing first models with different housing and service approaches. Other examples of successful programs called housing first include Direct Access to Housing (DAH), operated by San Francisco's Department of Public Health, which is aimed at housing people who are homeless and frequent users of medical emergency rooms, and a housing program operated by Seattle's Downtown Emergency Service Center that provides immediate access to an SRO room for people who are living on the streets and suffer from addiction disorders. These programs vary in type of housing provided (single site buildings vs. scattered site) and how services are provided (on site vs. off site). This variability of housing first approaches offers communities seeking to serve individuals or families who are chronically homeless a variety of program models: from a few scattered-site units with off-site case management support services to single site options of various sizes with services on site. Despite their differences, housing first programs share many dimensions: immediate access to housing with no treatment preconditions; services are optional; housing is permanent and affordable. Thus more communities are beginning to include a housing first option in their menu of programs options in continuum of care plans (Locke et al., 2007).

In the discussion of choice-based housing and services that follows, we focus on the Pathways' model for several reasons. The Pathways program is well researched and well documented, while also offering housing in the most integrated settings. In addition, the Pathways model not only centers on consumer choice, but the program is consumer driven. Consumers are integrated into every dimension of the program: planning, operation, and policy. Pathways has sustained its consumer-centered character by attending to the importance of consumer presence and voice at every level of the organization. All services promote individual self-determination and social integration. Thus upon admission, consumers choose their apartment and neighborhood of residence, restricted only by the availability of affordable housing. Because the independent scatter site apartments are leased from existing units in the community and comprise less than 20 percent of any building, while all program services are off site, both housing and services are offered in the least restrictive and most socially integrated settings. Finally, consumers are encouraged to fashion their own path towards greater social inclusion, whether through employment, returning to school, or reuniting with children.

In addition, several practices promote consumer voice more broadly within the agency: (1) as tenants, consumers participate on an advisory committee that meets with agency heads to express tenant concerns and to provide programmatic input; (2) every officer of the organization has an open door policy to all tenants; (3) consumers are hired as service providers and managers and are elected as members of the agency board of directors; (4) in meetings, accommodations ensure full participation—appointing a moderator, taking turns speaking, and having an active, moderated, question and answer period; and (5) social and recreational events provide opportunities for staff and consumers to meet informally and expand the repertoire of their dialogue. Both the organizational environment and service approach foster empowerment for greater community, civic, and political participation.

Research on housing first. A series of increasingly rigorous studies, conducted over several years, in different settings and with different subsets of the homeless population have focused mainly on the pathways to housing model and its replications. The studies summarized here have begun to establish an evidence base for housing first as an effective approach to ending homelessness and achieving positive outcomes in mental health and other domains.

Early findings. Early work focused on Choices Unlimited, a drop-in center and forerunner of Pathways to Housing. The program was funded as one of six multisite NIMH-McKinney research demonstration projects. The goal was to test a psychiatric rehabilitation approach to engaging consumers. The program did not impose treatment requirements, predetermine lengths of stay, or require that services be used in a given sequence as conditions for drop-in center use. To test the effectiveness of the approach, potential participants were randomly assigned to either the experimental program or to traditional outreach and drop-in center programs focused on housing readiness. Over two years of follow-up, time spent on the street declined for both groups, but the 55 percent decrease for the experimental group was almost twice the decrease (28 percent) for the control group (Tsemberis et al., 2003). Those in the experimental group also found it easier to obtain food, find a place to sleep, and remain sober than did the control group; they participated in more services, including day programs and self-help groups; and they received more help with alcohol and drug problems, financial entitlements, and health insurance (Shern et al., 2000). However, after 24 months only 38 percent of participants had moved to permanent housing. This finding guided program developers to focus on reducing barriers to housing access more directly by providing immediate access to independent scattered-site apartments and services based on consumer choice.

Housing retention. The housing first approach, which evolved from the Pathways to Housing drop-in center work, was initially investigated in a study that used administrative data to compare housing retention of housing first tenants to housing retention of tenants in supportive housing programs that required treatment and sobriety as preconditions to housing. Controlling for the effects of client characteristics, this study showed that participants in housing first achieved better housing tenure than did the comparison group (Tsemberis & Eisenberg, 2000). After five years, 88 percent of housing first participants remained housed, compared to 47 percent of those in more traditional housing programs. However, in the absence of random assignment, it is impossible to be sure that the better outcomes were due to program effects rather than unmeasured participant characteristics.

A subsequent experimental and longitudinal study of the effectiveness of the housing first approach in New York City was conducted as part of a SAMHSA multisite study of homelessness prevention. In this four-year study, 225 participants with severe mental illness, who were literally homeless and many diagnosed with co-occurring substance use disorders, were randomly assigned to receive either housing first or services as usual. Participants were interviewed every six months to examine changes across a range of outcomes, including residential status, substance use, and psychiatric symptoms. After six months, 79 percent of housing first participants were living in stable housing compared to 27 percent of participants in the control group (Tsemberis et al., 2003); and throughout two years of follow-up, housing first participants spent more time in stable housing and showed far greater reductions in homelessness than the control group (Tsemberis, Gulcur & Nakae, 2004).[9]

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[9]   After one year, participants in the Housing First Program spent 85 percent of their time stably housed, compared with less than 25 percent for participants in the services-as-usual group (Tsemberis, Gulcur, & Nakae, 2004) and the effect endured: After two years, housing first participants still spent approximately 80 percent of their time stably housed, compared with only 30 percent for the control group. Rates of homelessness decreased dramatically for Housing First tenants, who had spent approximately 55 percent of the period before baseline literally homeless, dropping to 12 percent at one year, and less than 5 percent after two years. Reductions in homelessness were significantly slower and less dramatic for the control group, who were homeless about 50 percent of the time at baseline, 27 percent at one year, and 25 percent after two years.

Another experimental study examined housing retention among long-term shelter dwellers with psychiatric disabilities and often co-occurring addictions in a suburban county. Participants were randomly assigned to one of two programs using housing first approaches (Pathways to Housing or a local consortium) or a services-as-usual control group. Replicating and extending previous findings, this study demonstrated that participants assigned to housing first obtained permanent, independent housing at higher rates than the control group. A majority of consumers housed by both housing first programs retained their housing over four years, with78 percent of participants in Pathways to Housing remaining housed over that period (Stefancic & Tsemberis, in press). This suggests that housing first services can be successfully replicated in non-urban environments and with a population of homeless persons with extensive shelter histories. These findings have been replicated with shelter populations in Salt Lake City (Flynn, 2006) and Hartford (White, 2005).

In 2003, a Collaborative Initiative to Help End Chronic Homeless was coordinated by the Interagency Council on Homelessness (ICH) and funded by HUD, HHS (SAMHSA and HRSA), and the VA to provide housing and services to chronically homeless populations. Seven of the eleven programs funded used the Pathways housing first model to provide scattered-site housing and off-site support and treatment services. They achieved similar housing retention results, with approximately 80 percent stably housed after 12 months (Rosenheck, 2006), successfully replicating both the model and the findings on retention across diverse contexts.

In domains other than retention, the results of several of these studies, including two controlled trials, are building a case for housing first as an evidence-based practice for addressing homelessness: Participants in housing first obtained housing earlier and remained stably housed at higher rates than control groups receiving services as usual through more traditional housing and treatment programs (Tsemberis, Gulcur, & Nakae, 2004; Gulcur et al., 2003). Further, housing first participants spent significantly less time in psychiatric hospitals and incurred fewer residential costs than controls (Gulcur et al., 2003), though findings from another study showed modest increases in societal costs for housing first (Rosenheck et al., 2003), suggesting a need for further examination in this domain.

Psychiatric symptoms and consumer choice. Further analyses of the housing first experimental data focused on psychiatric symptoms. Although housing first participants used fewer psychiatric treatment services than control group participants at every time point, there were no significant differences in self-reported symptomatology (Padgett, Gulcur, & Tsemberis, 2006), suggesting that optional participation in treatment services is as effective as mandatory participation in services. An examination of the relationship between stable housing and psychiatric symptoms shows a reduction in psychiatric symptoms if the person has been stably housed for the preceding six months (Tsemberis & Fischer, under review). Separate analyses compared the impact of consumer choice, a principal component of housing first, on the mental health of housing first and control participants. Ratings of perceived choice were significantly higher for participants in housing first compared to those in the control group; and perceived choice significantly accounted for a decrease in psychiatric symptoms, a relationship that was partially mediated by mastery (perceptions of personal control) (Greenwood et al., 2005). This strong and inverse relationship between perceived choice and psychiatric symptoms supports expansion of all housing models that increase consumer choice, thereby enhancing mastery and decreasing psychiatric symptoms.

Substance use and consumer choice. In a recent study Milby and colleagues (2005) examined the effectiveness of providing direct access to housing to individuals who were homeless and experiencing

cocaine dependence disorder. A total of 196 participants were assigned to receive: a) abstinence-contingent housing; b) non-abstinence contingent housing; or c) no housing. Participants were followed for 24 weeks. While the abstinence housing group showed significantly higher rates of abstinence (as required by the housing program) than the non-abstinence contingent group, results for days housed showed that "the groups did not differ significantly from each other at any time point." The investigators' conclusion favors abstinence-contingent housing, and the study's findings have been described as contradicting the positive findings on housing first. However, the focus on abstinence as the critical outcome reflects the study's focus on treating addiction rather than ending homelessness and obscures the important findings on housing tenure. The data clearly show also that for individuals with addictive disorders, housing without abstinence contingency is as effective as abstinence-contingent approaches in addressing homelessness. In New York City, Project Renewal, one of the HUD Chronic Inebriates Initiative sites, obtained similar results. Using a housing first approach with people who were frequent users of their detox services, this program achieved an 80 percent housing retention rate for non-abstinence contingent housing (Ed Geffner, personal communication, October 31, 2006). In a later program intervention, as one of the HUD's chronic inebriate grantees, Project Renewal decided to vary their approach and required 90 days of abstinence and treatment prior to providing housing for their second HUD program (calling the approach "housing-second"). Results indicated that the number of people who lost housing due to relapse into alcoholism was higher in the housing-second program (Cowles, 2007).

At another HUD Chronic Inebriates site, Pathways to Housing DC (a Pathways replication site), 35 of 36 people who were chronically inebriated were still housed after the first six months, and there was a reduction in (average) expenditures on alcohol from $87.06 a month prior to entering the program to $17.90 per month after entering into housing. Furthermore, results indicated that consumers who chose to participate in drug treatment had significantly reduced their consumption (Kent, 2007).

The experimental study of 225 housing first participants also examined substance use outcomes. Analyses show that although the services-as-usual group utilized more substance use *treatment*, there were no significant differences in self-reported substance *use* between the control and Housing First groups. Moreover, though the control group's greater service use continued over the four-year follow-up period, absence of group differences in alcohol and drug *use* persisted over the four-year period as well (Padgett, Gulcur, & Tsemberis, 2006).

Consumer satisfaction and challenges. While evidence for housing first has been accumulating, many providers continue to view the approach as appropriate only for high functioning individuals. This issue was addressed in a quasi-experimental study that compared differences in housing, psychiatric outcome, and satisfaction of formerly homeless participants in housing first and another supported housing model *versus* those in structured, service-intensive community residences (Siegel et al., 2006). Because participants were not randomly assigned to housing groups, a statistical procedure called propensity scoring was used to categorize participants into three strata depending on how they ranked as candidates for supported housing. Regardless of stratum, individuals in supported housing remained stably housed, and housing type had no effect on tenure. However, at every follow-up point, participants in supported housing reported greater satisfaction in terms of autonomy and economic viability than those in community residences.

Some participants in this study who were in supported housing, but who were ranked as more likely candidates for community residences, reported greater isolation, a finding also supported by a qualitative

study of community integration of housing first consumers. The qualitative study found that, for most consumers, entering housing after a long period of homelessness was associated with improvements in several psychological aspects of integration (e.g., a sense of fitting in and belonging) as well as feelings of being "normal" or part of the mainstream human experience. However, the study also uncovered challenges faced by housing first participants, including difficulties in coping with loneliness, adjusting to living independently, feeling safe without any monitoring presence, and "fitting in" in the community (Yanos, Barrow, & Tsemberis, 2004).

The weight of the evidence. Participants in housing first obtain and maintain independent housing with consumer-chosen supports without negative effects on psychiatric or substance use symptoms. Housing retention rates remain around 80 percent for periods of four to five years. And consumers in housing first report higher levels of choice and residential satisfaction compared with participants of more traditional programs. Further, consumer choice—a key aspect of housing first services—positively affects psychiatric symptoms, a relationship that is mediated by mastery (perceived choice leads to increased mastery, which is associated with reduced psychiatric symptoms). Finally, providing housing first has been shown to be less costly than traditional residential treatment, though it may be associated with modest increases in societal costs. Further research is now underway on fidelity measures of housing first that define the model's key features and assess how closely they are approximated as this rapidly disseminating model is implemented in diverse contexts and with various consumer subgroups.

Harm Reduction, Choice, and Homelessness

The predominant approach of housing programs for people who are homeless and dually diagnosed requires psychiatric treatment and a period of sobriety as preconditions for permanent housing. Specific variants include therapeutic communities, modified therapeutic communities, residences for "mentally ill chemical abusers" (MICAs), and other abstinence-based housing programs. (For a recent review see Center for Substance Abuse Treatment, 2005.) This approach has a documented history of clinical success for consumers who choose or are able to complete the programs and is favored by providers because it limits liability risks and management problems, and is consistent with the widely held view that people with dual disorders are unlikely to maintain housing without first developing housing readiness.

The programs presented here are focused on how substance use affects the efforts of persons who are homeless to obtain housing as opposed to treatment. As noted previously, abstinence-contingent housing can serve to exclude subgroups of people with dual diagnoses, thus leaving a significant proportion of individuals chronically homeless. Abstinence-contingent housing and treatment models usually emphasize, if not mandate, participation in 12-step mutual support groups (AA or NA). Despite the overall strength of their peer-based approach, abstinence programs tend to be stringently and hierarchically structured, with consumer choice and input significantly circumscribed beyond the initial choice to participate. For these reasons, and because these models are not a new development in the last 10 years and thus beyond the scope of this report, we have not reviewed them as "choice-based" approaches. By eliminating sobriety and psychiatric treatment as a preconditions for housing, housing first programs have proven highly effective in housing—and keeping housed—people with addiction disorders and dual disorders who had repeatedly failed in or been rejected by other programs.

Consumer choice is the foundation of the harm reduction approach (Inciardi & Harrison, 2000), in which consumers define their needs and goals as well as the pace and sequence of services. Harm reduction has emerged as an alternative to the ubiquitous 12-step abstinence/sobriety models of drug use and addiction

(Marlatt, 1998). As applied to homelessness, this gradual approach of encouraging consumers to reduce substance use and related risks replaces the pervasive sobriety and psychiatric treatment requirements that prevent individuals who are homeless from attaining and retaining housing (Rowe, Hogue, & Fisk, 1996). It offers an individualized approach to assisting consumers' progress towards recovery but starting at their stage of readiness for change rather than insisting on abstinence as a prerequisite for housing (Tsemberis & O'Callaghan, 2004). Harm reduction is consumer driven and seeks to minimize personal harm and adverse societal effects of substance abuse while the consumer strives towards recovery.[10]

Although sobriety and abstinence are considered ideal outcomes of harm reduction, the model allows alternative paths to sobriety as long as they serve to contain or reduce the many risks or risk behaviors associated with addiction, such as drug overdose, incarceration, impoverishment, prostitution, malnourishment, chronic homelessness, and ill health. Consequently, consumers are offered a range of treatment alternatives, which can include AA/NA, and are supported in making positive steps towards recovery, whether it means striving for abstinence or making use less risky. Harm reduction approaches often incorporate DiClemente and Prochaska's transtheoretical model of addiction and recovery, often referred to as the "stages of change model,"[11] to help consumers and clinicians define and track gradual goals on the path to attaining the ideal of sobriety (DiClemente, 2003; Prochaska & DiClemente, 1992; Marlatt, 1998).

In treatment for dually diagnosed populations, harm reduction works particularly well with other evidence-based practices, such as integrated dual-diagnosis treatment (IDDT) (Mueser et al., 2003) and illness management recovery (IMR). When housing programs for individuals who are dually diagnosed require abstinence as a condition for obtaining housing or for remaining housed, consumers with histories of substance abuse who are at risk of relapse are also at risk for housing loss and continued homelessness. This fear of eviction inhibits consumers who begin to use drugs or to experience psychiatric symptoms from discussing their emerging problems with housing counselors. Housing first programs separate the terms and conditions for continued tenancy from treatment concerns and provide integrated services that encourage honest feedback from consumers, including disclosure that they are using drugs or alcohol or no longer taking their psychiatric medication without fear that this will lead to eviction (Tsemberis & Asmussen, 1999).

Harm reduction approaches to homelessness for consumers with dual diagnoses. In some locales, harm reduction is codified as public policy, which requires its application to housing approaches that address homelessness. Thus, for example, harm reduction principles are central to San Francisco's Direct Access to Housing program, which creates integrated SRO housing developments to address homelessness for people with dual diagnoses. A descriptive study found that in these contexts, tenants with addictions were not at elevated risk of housing loss, and 70 percent retained housing over two years (Barrow et al., 2004).

The housing first approach implemented by Pathways to Housing is the most extensively described and researched homelessness intervention based on harm reduction principles. As described above, Pathways

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[10] Among its early applications, needle exchange programs designed to mitigate needle-related infectious disease transmission were prominent (Langendam et al., 2001). More recent applications include jail diversion programs to reduce the psychological, economic, and socially hazardous conditions incurred during incarceration (Klein, 1997).

[11] The stages of change are precontemplation, contemplation, preparation, action, and maintenance.

imposes neither abstinence nor treatment conditions for accessing or remaining in housing. The program offers consumers access to an interdisciplinary ACT team of skilled clinicians who offer integrated dual diagnosis treatment (IDDT) and other assistance on the person's own terms. Those who continue to use addictive substances or remain symptomatic may go in and out of treatment but they are not at risk of housing loss. Some newly housed consumers are motivated to reduce substance use or seek psychiatric treatment because they desperately want to avoid jeopardizing their newly-obtained housing (which, in some cases, is the first housing they have ever been able to call their own). Once survival is assured through housing, others may seek treatment for psychiatric symptoms or become ready to address other needs such as employment or family reunification (Tsemberis & O'Callaghan, 2004).

Previously cited evidence from experimental studies shows housing first participants have dramatically better homelessness outcomes and show equivalent levels of substance use compared to participants in services-as-usual programs that do not employ harm reduction (Padgett, Gulcur, & Tsemberis, 2006). While a specific test of abstinence-contingent housing versus non-abstinence contingent housing reported the unsurprising result of higher rates of abstinence in the housing program that required it, investigators report no difference in housing retention (Milby et al., 2006). Given that the most important outcomes for dually-diagnosed consumers who are homeless are either neutral or improved when harm reduction is employed, the study supports a harm reduction approach to homelessness and substance addictions among people with co-occurring addiction and mental illness.

Harm reduction approaches for consumers with long-term substance addictions. In 2006, a Health Care for the Homeless Council position statement endorsed including harm reduction models of addiction treatment in SAMHSA's best practices. The statement notes that programs that incorporate harm reduction strategies are "more likely to attract active users (and hence those most in need of resources for reducing drug-related harm), enhance motivation for positive change, improve retention in treatment, and reduce attrition and premature termination of services" (National Health Care for the Homeless Council, 2006). Canada Mortgage and Housing Corporation's brief review (2005) of homeless assistance programs that use harm reduction approaches describes a dozen programs in the United States, Canada, and the United Kingdom. Most provide permanent housing in dedicated units or scattered sites. To minimize harms associated with high-risk behaviors, programs emphasize helping residents reduce their usage, focusing on the strengths and capacities of the person rather than on the substances they consume, and encouraging changes in consumption habits (e.g., a move to less harmful substances, safe disposal of used syringes) or ensuring that there is not an increase in use. All emphasize the consumer-determined pace and content of services. Descriptions of harm reduction programs specifically addressing alcohol addiction among people with long-term homelessness include a Canadian report on a "managed alcohol" intervention (Podymow et al., 2006) and Anishinabe Wakiagun, a Minnesota program that provides permanent housing and case management services addressing health and support needs of men and women with late-stage chronic alcoholism and extensive homelessness (Canada Mortgage and Housing Corporation, 2005).

Research on programs that use harm reduction principles in housing for people with chronic homelessness and long-term alcohol dependence remains rudimentary (Hwang, 2006). A "managed alcohol" intervention was studied by Podymow and colleagues (2006), who used pre- and post- measures to assess changes in 17 program participants. They documented significant decreases in both emergency room visits and encounters with police. Participants also spent fewer days in the hospital and self-reported decreases in alcohol use. Such initial reports indicate that this harm reduction approach deserves serious attention in future research with this group.

Implications for Preventing and Ending Homelessness

In the last decade, people who have experienced homelessness have claimed increasingly active roles in research, policy, planning, and service delivery, and have furthered the expansion of choice-based alternatives to existing housing and service policies. We summarize here what the literature on these processes implies for the participating consumers; for homelessness research, policy, and service processes; and for efforts to end homelessness at a system or population level.

Implications of Consumer Involvement in Research, Policy, and Planning

Ethics and social justice argue for a prominent role for consumers who have experienced homelessness in research, planning, and policy-making, and a descriptive literature documents a large expansion of such roles. Qualitative accounts of experiences of consumers in these arenas make a persuasive case that, with adequate support, consumer involvement produces both benefits for consumers and improvements in research and policy.

Individual-Level Impacts on Consumers

- With appropriate support, participation in research, planning, and policy offers consumers practical benefits (employment, skills) as well as personal growth and improved self-confidence.

Implications for Research, Policy, and Planning Processes

- Effective consumer involvement in research, policy, and planning requires organizational support to address barriers, avoid tokenism, and authorize consumer decision-making.

- When supported, integration of consumers adds to the relevance, validity, and sensitivity of homelessness research, service planning and policy making.

Implications for Ending Homelessness at a Population Level

- Local consumer advocacy groups have pressed for the structural interventions (e.g., affordable housing) necessary to end homelessness at a population level. Consumer voices can make a unique contribution to leverage what must ultimately be a broad collaborative effort to restructure the systems that have thus far failed to do this.

Implications of Consumer Involvement in Service Delivery

Consumer employment has increased notably in homeless services as well as in self-help and consumer-operated programs for mental health consumers. Outcome studies show peer service delivery is effective and distinctive, but requires appropriate institutional support.

Implications for Service Recipients

- With adequate support and accommodation, peer staffing in homelessness programs is as effective as traditional services in helping service recipients spend less time homeless.

- Certified Peer Specialist (CPS) programs are expanding opportunities for consumer staffing, but as yet there is no research evaluating the effects of these programs on homelessness or other outcomes.

- New research on consumer-operated services shows that recovery-related program features are associated with improved well-being; but the research was not designed to examine effects on homelessness.

Implications for Service Processes and for Homeless Service Systems

- Consumer-provided services share distinctive emphases (e.g., respect, support, and agency) and a work culture emphasizing support and less use of authority to leverage compliance.

- Integrating consumer staff into traditional settings requires providing preparation, support, and supervision and addressing boundary issues, stigma, and discrimination.

Implications for Ending or Preventing Homelessness at a Population Level

- Consumer-staffed and consumer-run programs have not typically focused on the system-level changes required to end homelessness at a population level.

Implications of Consumer-Driven and Choice-Based Housing and Service Approaches

Over the last decade, consumer-driven approaches to homeless services—particularly the housing first model—have moved from the service and policy margins to a visible, and even central, place in many locales' 10-year plans to end homelessness.

Individual-Level Impacts on Homelessness

- Increasingly rigorous studies have shown that housing first produces better housing outcomes than alternatives that emphasize housing readiness for people with co-occurring disorders who experience homelessness. There is some research evidence that it reduces residential costs for participants.

- Harm reduction is integral to the housing first model. In studies of housing first, tenants have less contact with psychiatric and substance use services than do control groups engaged in usual services, but critics' fears of escalating substance use and psychiatric symptoms in the absence of treatment and abstinence requirements have proven unfounded.

- Research is needed on new harm reduction housing for people with chronic addictions, which as yet have only anecdotal support as a strategy for ending homelessness.

System-Level Impacts

- The endorsement of housing first in 10-year plans and the broad dissemination of this model currently underway implies significant change in homelessness policy and practice. Widespread adoption of the housing first model would both entail transformation of existing systems for delivering homeless services and housing.

- Since it relies on existing housing stock, any broad-based implementation of housing first in locales lacking adequate affordable housing must be accompanied by expansion of the supply of low-cost housing if it is to play a significant role in ending homelessness at the population level. This will require advocacy for affordable housing from broad sectors of society, extending well beyond those most affected by and concerned with homelessness.

- Because it challenges central features of current housing/service approaches (housing readiness, congregate housing, on-site services), widespread implementation must address the mismatch with existing funding and service models.

Research Recommendations and the Policy Issues They Address

Based on our review of the literature on consumer roles in research, policy, planning, and services delivery and our assessment of consumer-driven service/housing approaches, we offer the following inventory of unresolved policy issues and a set of recommendations about the research necessary to address them.

Can the lessons learned about approaches to and consequences of consumer integration in multisite research initiatives be extended to policy and planning settings? In what ways will policies developed with full integration of people who have experienced homelessness differ from policies made with more limited or no consumer involvement? Consumer voices were not prominent in the processes that led to current systems of homeless services. As a starting point to assess whether and how consumer integration changes not only the process of planning and policy-making but the direction of policy itself, we recommend using qualitative approaches (ethnography, oral history, elicited narratives) to document processes and impacts of consumer involvement on policy bodies, such as HUD continuum of care planning committees, HCH governing bodies, and other homelessness policy and planning venues. The work of the consumer panels of the several homelessness-related SAMHSA multisite research initiatives offers important lessons on the supports needed to overcome barriers to consumer integration as well as approaches to documenting process and impact of consumer participation.

How can efforts to expand consumer integration in homelessness research, policy, planning and services address the experiences of consumers of color and avoid replicating the exclusions and stigmatization that are structured by societal mechanism of racial exclusion and poverty? Structural mechanisms (racial exclusion, poverty, lack of housing) that promote homelessness and direct its impact to poor communities of color also inhibit consumer integration in homelessness research, policy, planning and service delivery. Multi-level research and advocacy collaborations are needed to explore the links between these systemic processes and the barriers consumers of color experience, educate all involved with homelessness about these links, and connect consumers and advocates with broader social movements that address racial exclusion.

Research shows peer-staffed programs provide clients who are homeless with equivalent services and achieve outcomes equivalent to those achieved by non-consumer teams. Will expansion of peer employment opportunities through policies to certify and obtain Medicaid reimbursement for peer services affect staffing in homeless services, and with what impact on outcomes of individuals receiving services? The recent growth of various types of certified peer specialist programs offers an important opportunity to assess the impact of key dimensions of variation (training, certification, Medicaid

reimbursement) on consumer employment in homeless service settings. In addition to documenting the range of program approaches deployed in these settings, research should address effects of CPS programs and other peer employment on peer staff as well as in promoting housing stability and other desired outcomes for persons who are homeless.

Experimental research on recovery-focused consumer-operated service programs has demonstrated effects on well-being. Can such services be effective in resolving homelessness and extending housing tenure? The research evidence for consumer-operated service programs has not specifically examined how such programs address homelessness and with what impact. Although findings are suggestive, there is need for research that specifically examines how consumer-operated services address homelessness and with what effects.

As housing first programs are replicated in different contexts and with new populations, what variations are introduced? How are outcomes affected? Much of the evidence for housing first is based on research on the Pathways to Housing program where the model originated. Fidelity studies currently in process will facilitate necessary further research on the model's effectiveness and cost effectiveness in varied contexts—with differently structured housing markets and contrasting service cultures as well as in diverse homeless subgroups (families, young adults aging out of foster care, and justice-involved individuals).

Is harm reduction housing a viable alternative to existing abstinence policies for people with long-term substance addictions and homelessness? While harm reduction has been part of the housing first approach as applied in programs for people with co-occurring mental illness and substance use, harm reduction housing for persons with histories of chronic homelessness and long-standing alcohol dependence or extensive drug use is relatively new and as yet untested. Descriptive studies are needed to document these interventions and their outcomes as are more rigorous controlled studies that evaluate their effectiveness in addressing homelessness and their impact on quality of life, health, and other outcomes. Anecdotal evidence supports the cost-effectiveness of these interventions; however little is known of outcomes and costs over time. Although the approach may remain controversial, it may offer new hope for those who have not found abstinence-focused programs to be a viable route to recovery.

A Final Note. As consumers increase their presence in the venues where decisions are made about homelessness research, policy, and service delivery, it is tempting to see consumer integration as the answer to homelessness. For many individuals who have been homeless, such participation will surely hasten personal recovery and social reintegration following homelessness, and their involvement will surely produce more responsive and effective policies. To expect that consumer integration or consumer-driven service programs alone will end homelessness at a societal level, however, is to overlook the multiple exclusionary processes—from global to local—that have generated homelessness by concentrating wealth, reducing the stock of affordable housing, skewing the distributions of opportunities for income and educational achievement, and marginalizing large segments of minority and poor populations in prisons or other institutions. Consumer voices will articulate priorities, create and validate useful service approaches, and energize the social resolve to address homelessness. If we are serious about ending homelessness, *all* voices must join together to demand the creation of housing and the other tools necessary to get the job done.

References

Allen, M. (1996). Separate and unequal: The struggle of tenants with mental illness to maintain housing. *Clearinghouse Review, 30,* 720–739.

Anthony, W. A. (2000). A recovery-oriented service system: Setting some system level standards. *Psychiatric Rehabilitation Journal, 24*(2), 159–169.

Anthony, W. A., Cohen, M. R., Farkas, M., & Gagne. C. (2002). *Psychiatric rehabili*tation (2nd ed.). Boston: Center for Psychiatric Rehabilitation.

Anthony, W., Rogers E. S., & Farkas, M. (2003). Research on evidence-based practices: Future direction in an era of recovery. *Community Mental Health Journal, 39,* 101–114.

Barrow, S. M., Soto Rodriguez, G., & Córdova, P. (2004). *Final report on the evaluation of the Closer to Home Initiative*. Retrieved from http://documents.csh.org/documents/policy/cth_final.doc

Bartlett, O. (2006, January 13). *Current I/C practices on involvement of consumer advocates in peer review.*. Retrieved July 7, 2006, from http://grants.nih.gov/grants/peer/prac/prac_jan_2006/prac_minutes_20060123.doc

Bassuk, E. (2001). In *Better Homes Fund, Adding seats to the table: A community-based approach to family homelessness, Final Report* [Preface]. Newton, MA: Better Homes Fund.

Bazelon Center for Mental Health Law. (1998). *Partners in planning: Consumers' role in contracting for public-sector managed mental health and addiction services.* Washington DC: U.S. Department of Health and Human Services, Substance Abuse and Mental Health Services Administration.

Bebout, R. R., & Harris, M. (1992) In search of pumpkin shells: Residential programming for the homeless mentally ill. In R. Lamb, L. L. Bachrach, & F. Kass (Eds.), *Treating the homeless mentally ill: A report of the Task Force on the Homeless Mentally Ill* (pp. 159–181). Washington, DC: American Psychiatric Association Press.

Better Homes Fund. (2001). *Adding seats to the table: A community-based approach to family homelessness* (Final Report). Newton, MA: Author.

Bishop, G., & Brodkey, A. (2006). Personal responsibility and physician responsibility—West Virginia's Medicaid Plan. *New England Journal of Medicine, 355*(8), 756–758.

Boden, P., & Lozier, J. (2005). *Project to increase participation of HCH clients: Report and recommendations.* Retrieved July 12, 2007, from http://www.mccormack.umb.edu/csp/consumerhmis/PaulBodenConsumerReportDraft2.pdf

Boote, J., Telford, R., & Cooper, C. (2002). Consumer involvement in health research: A review and research agenda. *Health Policy, 61,* 213–236.

Bridgman, R. (2006). "We are the first youth": Participatory planning in transitional housing for suburban homeless youth. In M. M. Thomas-Houston & M. Schuller (Eds.), *Homing devices: The poor as targets of housing policy and practice* (pp. 141–158). Oxford: Lexington Books.

Broder, T. (2007). *Overview of immigrant eligibility for federal programs.* Retrieved August 22, 2007, from www.nilc.org

Buck, D. S., Rochon, D., Davidson, H., McCurdy, S., & HHH CHANGE committee. (2004). Involving homeless persons in the leadership of a health care organization. *Qualitative Health Research, 14*(4), 513–525.

Campbell, J. (2004). Consumer-Operated Services Program (COSP) *Multisite Research Initiative. Overview and preliminary findings.* Retrieved August 1, 2006, from http://www.power2u.org

Campbell, J. (2006a). The historical and philosophical development of peer-run support programs. In S. Clay (Ed.), *On our own, together* (pp. 17–64). Nashville: Vanderbilt University Press.

Campbell, J. (2006b). *Effectiveness findings of a large, multi-site study of consumer operated services 1998–2006.* Retrieved July 31, 2006, from http://www.psych.uic.edu/uicnrtc/nrtc4.webcast1.jcampbell.slides.pdf

Canada Mortgage and Housing Corporation. (2005). Homelessness, housing, and harm reduction: Stable housing for homeless people with substance use issues (Socio-economic Series 05-027). *Research Highlight,* 1–10.

Carling, P. J. (1993). Housing and supports for persons with mental illness: Emerging approaches to research and practice. *Hospital and Community Psychiatry, 44,* 439–449.

Carpinello, S. E., Knight, E. L., & Janis, L. (1991). *A qualitative study of the perceptions of the meaning of self-help, self-help group processes and outcomes.* Albany, NY: New York State Office of Mental Health.

Center for Substance Abuse Treatment. (2004). *Building bridges: Co-occurring mental illness and addiction: Consumers and service providers, policymakers, and researchers in dialogue.* Washington, DC: U.S. Department of Health and Human Services, Substance Abuse and Mental Health Services Administration, Center for Mental Health Services.

Center for Substance Abuse Treatment. (2005). *Substance abuse treatment for persons with co-occurring disorders*(Treatment Improvement Protocol (TIP) Series 42. DHHS Publication No. SMA 05-3922). Rockville, MD: Author.

Chinman, M. J., Rosenheck, R., Lam, J.A., & Davidson, L. (2000). Comparing consumer and nonconsumer provided case management services for homeless persons with serious mental illness. *Journal of Nervous and Mental Disease, 188,* 446–453.

Clarke, G., Herinckx, H., Kinney, R., Paulson, R., Cutler, D. L., Lewis, K., & Oxman, E. (2000). Psychiatric hospitalizations, arrests, emergency room visits, and homelessness of clients with serious and persistent mental illness: Findings from a randomized trial of two ACT programs versus usual care. *Mental Health Services Research, 2*(3), 155–164.

Clay, S. (Ed.). (2006). *On our own, together*. Nashville: Vanderbilt University Press.

Clay, S., Schell, B., Corrigan, P., & Campbell, J. (2006). With us: Where are we going? In: S. Clay (Ed.), *On our own, together* (pp. 239–258). Nashville: Vanderbilt University Press.

Copeland, M. E. (1997). *Wellness recovery action plan*. West Dummerston, VT: Peach Press.

Corrigan, P. W., & Watson, A. C. (2002). The paradox of self-stigma and mental illness. *Clinical Psychology: Science and Practice, 9,* 35–53.

Cowles, S. (2007, June). *Project Renewal's housing first programs: CHI and HUD chronic inebriates.* Presented at the annual meeting of the Supportive Housing Network of New York.

Dailey, E. (2003). *Consumer Advisory Board manual for Health Care for the Homeless projects* (pp. 1–9). Nashville: National Health Care for the Homeless Council.

Davidson, L., Chinman, M., Sells, D., & Rowe, M. (2006). Peer support among adults with serious mental illness: A report from the field. *Schizophrenia Bulletin, 32*(3), 443–450.

Davidson, L., Chinman, M., Kloos, B., Weingarten, R., Stayner, D., & Tebes, J. K. (1999). Peer support among individuals with severe mental illness: A review of the evidence *Clinical Psychology: Science and Practice, 6*(2), 166–187.

Davidson, N. M. (2006). "Housing First" for the chronically homeless: Challenges of a new service model. *Journal of Affordable Housing and Community Development, 15*(2), 125–136.

Deegan, P. E. (1988). Recovery: The lived experience of rehabilitation. *Psychosocial Rehabilitation Journal, 11*(4), 12–19.

Deegan, P. E. (2007). The lived experience of using psychiatric medication in the recovery process and a shared decision-making program to support it. *Psychosocial Rehabilitation Journal, 34*(1), 62–69.

Deming, M., McGoff-Yost, K., & Strozier, A. (2002). Homeless addicted women, in S. L. A. A. Straussner, & S. Brown (Eds.), *The handbook of addiction treatment for women: Theory and practice* (pp. 451–469). San Francisco: Jossey-Bass,

DiClemente, C. C. (2003). *Addiction and change: How addictions develop and addicted people recover.* New York: Guilford.

Edmundson, E., Bedell, J., & Gordon, R. (1984). The community network development project. In A. Garttner & F. Riesman (Eds.), *The self help revolution* (pp. 195–215). New York: Human Sciences Press.

Ellison, R. (1980). *Invisible man.* New York: Random House

EPPI Centre/Social Science Research Unit, Institute of Education, University of London. (n.d.). Retrieved August 20, 2006, from http://eppi.ioe.ac.uk/cms

Farmer, P. (2004). An anthropology of structural violence. *Current Anthropology, 45*(3), 305–325.

Felton, C. J., Stastny, P., Shern, D. L., Blanch, A., Donahue, S. A., Knight, E., & Brown, C. (1995). Consumers as peer specialists on intensive case management teams: Impact on client outcomes. *Psychiatric Services, 46,* 1037–1044.

Fisk, D., & Frey, J. (2002). Employing people with psychiatric disabilities to engage homeless individuals through supported socialization: The buddies project. *Psychiatric Rehabilitation Journal, 26*(2), 191–196.

Fisk, D., Rowe, M., Brooks, R., & Gildersleeve, D. (2000). Integrating consumer staff members into a homeless outreach project: Critical issues and strategies. *Psychiatric Rehabilitation Journal, 23*(3), 244–252.

Flynn, M. (2006). *Introducing housing first to the Road Home shelter program: Outcomes from the first year.* Presented at annual meeting of National Alliance to End Homelessness, Washington DC.

Francis, L. E., Colson, P. W., & Mizzi, P. (2002). Ethics in community mental health care. Beneficence vs. obligation: Challenges of the Americans with Disabilities Act for consumer employment in mental health services. *Community Mental Health Journal, 38*(2), 95–110.

Fraser, N., & Honeth, A. (2003). Redistribution or recognition? A political-philosophical exchange. London: Verso.

Friere, P. (1972). *Pedagogy of the oppressed.* Harmondsworth, UK: Penguin

Galanter, M. (1988). Zealous self-help groups as adjuncts to psychiatric treatment: A study of Recovery, Inc. *American Journal of Psychiatry, 145*, 1248–1253.

Galanter, M. (1998). Cults and zealous self-help movements: A psychiatric perspective. *Psychiatric Services, 49*, 533–535.

Galanter, M. (2000). Self help treatment for combined addiction and mental illness. *Psychiatric Services, 51*(8), 977–979.

Gladwell, M. (2006, February 13 and 20). Million dollar Murray. Why problems like homelessness may be easier to solve than to manage. *New Yorker.*

Glasser, N. (1999) Giving voice to homeless people in policy, practice and research. In: L. Fosburg, & D. Dennis (Eds.), *Practical Lessons: The 1998 National Symposium on Homelessness Research* (pp. 5-1–5-17). Washington, DC: U.S. Department of Housing and Urban Development and U.S. Department of Health and Human Services.

Goering, P., Paduchak, D., & Durbin, J. (1990). Housing homeless women: A consumer preference study. *Hospital and Community Psychiatry, 4,* 790–794.

Goldfinger, S., & Schutt, R. (1996). Comparison of clinicians' housing recommendations and preferences of homeless mentally ill persons. *Psychiatric Services, 47*, 413–415.

Goldstrom, I. D., Campbell, J., Rogers, J., Lambert, D., Blacklow, B., Henderson, M., & Manderscheid, R. (2006). National estimates for mental health mutual support groups, self-help organizations, and consumer-operated services. *Administration and Policy in Mental Health and Mental Health Services Research, 33*(1), 92–103.

González Baker, S. (1996). Homelessness and the Latino paradox. In J. Baumohl (Ed.), *Homelessness in America* (pp. 132–140). Phoenix: Oryx Press.

Greenwood, R. M., Schaefer-McDaniel, N. J., Winkel, G., & Tsemberis, S. J. (2005). Decreasing psychiatric symptoms by increasing choice in services for adults with histories of homelessness. *American Journal of Community Psychology, 36*(3/4), 223–238.

Gulcur, L., Stefancic, A., Shinn, M., Tsemberis, S., & Fischer, S. N, (2003). Housing, hospitalization, and cost outcomes for homeless individuals with psychiatric disabilities participating in continuum of care and housing first programmes. *Journal of Community & Applied Social Psychology, 13,* 171–186.

Hartman, C. (Ed.). (2001). *Challenges to equality: Poverty and race in America*. Armonk, NY: M.E. Sharpe.

Hensley, M. (2006). Why I am not a "mental health consumer." *Psychiatric Rehabilitation Journal, 10*(1) 67–69.

Herinckx, H. A., Kinney, R. F., Clarke, G. N., & Paulson, R. I. (1997). Assertive community treatment versus usual care in engaging and retaining clients with severe mental illness. *Psychiatric Services, 10,* 1297–1306.

Homes for Families. (n.d.). Retrieved August 16, 2006, from http://www.homesforfamilies.org

Hopper, K. (2003). *Reckoning with homelessness.* Ithaca NY: Cornell University Press.

Hopper, K. (in press). Social recovery from schizophrenia: What a capabilities approach might add. *Social Science and Medicine.*

Hopper, K., & Barrow, S. (2003). Two genealogies of supported housing. *Psychiatric Services, 54*(1), 50–54.

Housing Works. (2005). *Housing Works strategic plan and visioning statement, 2005*. Retrieved October 14, 2006, from http://housingworks.org

Howard, P. B., & El-Mallakh, P. (2001). Training consumers to collect data in mental health service system evaluation research. *Journal of Psychosocial Nursing and Mental Health Services, 39*(5), 31–39.

Howie the Harp. (1993). Taking a new approach to independent living. *Hospital and Community Psychiatry, 44,* 413.

Hwang, S. (2006). Homelessness and harm reduction. *Canadian Medical Association Journal, 174*(1), 50–51.

Inciardi, J. A., & Harrison, L. D. (2000). Introduction: The concept of harm reduction. In J. A. Inciardi & L. D. Harrison (Eds.), *Harm reduction: National and international perspectives* (pp. 2–19).Thousand Oaks, CA: Sage.

Institute of Medicine. (2001). *Crossing the quality chasm: A new health system for the 21st century.* Washington, DC: National Academy Press.

Janzen, R., Nelson, G., Trainor, J., & Ochocka, J. (2006). A longitudinal study of consumer/survivor Initiatives: Part 4–Benefits beyond the self? A quantitative and qualitative study of system-level activities and impacts. *Journal of Community Psychiatry, 34*(3), 285–303.

Jewell, C., Davidson, L., & Rowe, M. (2006). The paradox of engagement: How political, organizational and evaluative demands can hinder innovation in community mental health services. *Social Service Review, 80*(1), 3–26.

Johnsen, M., Teague, G., & McDonel Herr, E. (2006). Common ingredients as a fidelity measure in peer-run programs. In S. Clay (Ed.), *On our own, together* (pp. 213–238). Nashville: Vanderbilt University Press.

Kaufman, C. L. (1995). The self-help employment center: Some outcomes from the first year. *Psychosocial Rehabilitation Journal, 13,* 520–524.

Kaufman, C. L., Schulberg, H. C., & Schooler, N. R. (1994). Self-help group participation among people with severe mental illness. In: F. Lavoie, T. Borkman, & B. Gidron (Eds.), *Self-help and mutual aid. International and multicultural perspectives* (pp. 315–331). Binghamton, NY: Haworth.

Kennedy, M. (1989). *Psychiatric hospitalization of GROWers*. Paper presented at the Second Biennial Conference of Community Research and Action, East Lansing, MI.

Kent, D. (2007, July 23). *Pathways' Chronic Inebriates Initiative: Program outcomes*. Presented at meeting with HUD survey group, Washington, DC.

Kirsh, B. (2000). Factors associated with employment for mental health consumers. *Psychiatric Rehabilitation Journal, 24*(1), 13–21.

Klein, A. R. (1997). *Alternative sentencing, intermediate sanctions and probation* (2nd ed.). Cincinnati, OH: Anderson.

Kuhn, R., & Culhane, D. (1998). Applying cluster analysis to test a typology of homelessness by pattern of public shelter utilization. *American Journal of Community Psychology, 17*(3), 23–43.

Kurtz, L. F. (1988). Mutual aid for affective disorders: The manic depressive and depressive association. *American Journal of Orthopsychiatry, 58,* 152–155.

Langendam, M. W., van Brussel,G. H. A ., Coutinho, R. A., & van Ameijden, E. J. C. (2001). The impact of harm-reduction-based methadone treatment on mortality among heroin users. *American Journal of Public Health, 91,* 774–780.

Lecomte, T., Wilde, J. B., & Wallace, C. J. (1999). Mental health consumers as peer interviewers. *Psychiatric Services, 50*(5), 693–695.

Lewin, K. (1946). Action research and minority problems. *Journal of Social Issues, 2,* 34–46.

Link, B., & Phelan, J. (2001). Conceptualizing stigma. *Annual Review of Sociology, 27,* 363–385.

Link, B., & Phelan, J. (1995). Social conditions as fundamental causes of disease [Extra issue]. *Journal of Health and Social Behavior, 35,* 80–94.

Locke, G., Khadduri, J., & O'Hara, A. (2007, March 1–2). Housing models. Paper presented at 2007 National Symposium on Homelessness Research, Washington, DC.

Lovell, A. M., & Cohen, S. (1998). The elaboration of "choice" in a program for homeless persons labeled psychiatrically disabled. *Human Organization, 57,* 8–20.

Markowitz, F., DeMasi, M., & Carpinello, S. (1996). *The role of self-help in the recovery process.* Paper presented at the sixth annual National Conference on State Mental Health Agency Services Research and Program Evaluation, Arlington, VA.

Marlatt, G. A. (1998). Basic principles and strategies of harm reduction. In G. A. Marlatt (Ed.), *Harm reduction: Pragmatic strategies for managing high-risk behaviors*. New York: Guilford Press.

McMullin, L., & Pennington, L. (2005). *Continued trauma in the lives of mothers who are homeless.* Presented at the American Public Health Association Meeting, Philadelphia, PA.

McMullin, L., & Reid, C. (2003, February 10). *Consumer impact on designing evidence-based interventions for homeless mothers with mental health and substance abuse treatment needs.* Presented at the National Association of State Mental Health Program Directors Conference on State Mental Health Agency Services Research, Baltimore, MD.

McMullin, L., Grassette, A., Pennington, L. H., Birckett, S., Cole, L., Heller, L., et al. *Establishing consumer integration in the evaluation of the SAMHSA Homeless Families Program.* Manuscript in progress.

Mechanic, D. (1999). *Mental health and social policy. The emergence of managed care.* Boston: Allyn and Bacon.

Mead, S., & Copeland, M. (2000). What recovery means to us: Consumers' perspectives. *Community Mental Health Journal, 36,* 315–328.

Meyers, E. (2002). *The role of consumers in improving the validity of individual and multi-site efforts.* Presented at the annual meeting of the American Evaluation Association.

Milby, J. B., Schumacher, J. E., Wallace, D., Freedman, M. J., & Vuchinich, R. E. (2005). To house or not to house: The effects of providing housing to homeless substance abusers in treatment. *American Journal of Public Health, 95,* 1259–1265.

Miller, L., & Miller, L. (1997). A.N.G.E.L.S., Inc. consumer-run supported employment agency. *Psychiatric Rehabilitation Journal, 21,* 160–163.

Miller, W., & Rollnick, S. (2003). *Motivational Interviewing: Preparing people for change* (2nd. ed.). New York: Guilford Press.

Minkler M., & Wallerstein N. (Eds.). (2003). *Community-based participatory research for health.* San Francisco: Jossey-Bass.

Mockus, S., Mars, L. C., Ovard, D. G., Mazelis, R., Bjelajac, P., Grady, J., et al. (2005). Developing consumer/survivor/recovering voice and its impact on services and research: our experience with the SAMHSA Women, Co-Occurring Disorders and Violence Study. *Journal of Community Psychology, 33*(4), 513–525.

Moos, R., Schaefer, J., Andrassy, J., & Moos, B. (2001). Outpatient mental health care, self-help groups, and patients' 1-year treatment outcomes. *Journal of Clinical Psychology, 57, 1–15.*

Mowbray, C. T., Moxley, D. P., & Collins, M. E. (1998). Consumers as mental health providers: First person accounts of benefits and limitations. *Journal of Behavioral Health Services and Research, 25*(4), 397–411.

Mowbray, C. T., Wellwood, R., & Chamberlain, P. (1988). Project Stay: A consumer-run support service. *Psychosocial Rehabilitation Journal, 12,* 33–42.

Mueser, K. T., Noordsy, D. L., Drake, R. E., & Fox, L. (2003). *Integrated treatment for dual disorders: A guide to effective practice.* New York: Guilford.

Mueser, K. T., Corrigan, P. W., Hilton, D. W., Tanzman, B., Schaub, A., Gingerich, S., et al. (2002). Illness management and recovery: A review of the research. *Psychiatric Services, 53*(10), 1272–1284.

National Association of State Mental Health Program Directors. (2005). Position statement on housing and supports for individuals with mental illness Retrieved December 14, 2006, from http://www.nasmhpd.org/position_statement.cfm

National Mental Health Association. (2006). MHA-sponsored programs for people who are homeless. Retrieved October 27, 2006, from http://www.nmha.org/homeless/homelessnessAffiliatePrograms.pdf

National Mental Health Association of Southeastern Pennsylvania. (2006, July 27). *National Professional Organization of People in Recovery from Psychiatric Disabilities is created* [Press release]. Retrieved January 12, 2007, from http://www.mhasp.org/presspeer.pdf

National Mental Health Consumers' Self-Help Clearing House. (n.d.). *Starting a self-help/advocacy group.* Retrieved July 6, 2006, from http://www.mhselfhelp.org

Nelson, D. E., Fleming, D. W., Grant-Worley, J., & Houchen, T. (1995). Outcome-based management and public health: The Oregon Benchmarks experience. *Journal of Public Health Management Practice, 1*(2), 8–17.

Nelson, G., Hall, G. B., & Walsh-Bowers, R. (1998). The relationship between housing characteristics, emotional well-being and the personal empowerment of psychiatric consumer/survivors. *Community Mental Health Journal, 34*(1), 57–69.

Nelson, G., Ochocka, J., Janzen, R., & Trainor, J. (2006). A longitudinal study of mental health consumer/survivor initiatives: Part 1: Literature review and overview of the study. *Journal of Community Psychology, 34*(3), 247–260.

New Freedom Commission on Mental Health. (2003). *Achieving the promise: Transforming mental health care in America. Final report* (DHHS Pub. No. SMA-03-3832). Rockville, MD: Author.

New Freedom Commission on Mental Health. (2003) Subcommittee on employment and income support. Retrieved September 2, 2006, from http://govinfo.library.unt.edu/mentalhealthcommission/minutes/march03.htm

New York City Continuum of Care. (2006). Continuum of care application summary, Retrieved August 23, 2006, from http://www.nyc.gov/html/dhs/downloads/pdf/2006nofa_schedule.pdf

Nilsen, E. S., Myrhaug, H. T., Johansen, M., Oliver, S., & Oxman, A. D. (2006). Methods of consumer involvement in developing healthcare policy and research, clinical practice guidelines and patient information material (Review). *Cochrane Library,* (3), 1–25.

Nixon, J., Walker, M., & Baron, S. (2002). From Washington Heights to the Raploch: Evidence, mediation, and the genealogy of policy. *Social Policy & Society, 1*(3), 237–246.

Nussbaum, M. (2000). *Women and human development: The capabilities approach.* New York: Cambridge University Press.

Ochocka, J., Nelson, G., Janzen, R., & Trainor, J. (2006). A longitudinal study of mental health consumer/survivor initiatives: Part 3—A qualitative study of the impacts of participation on new members. *Journal of Community Psychology, 34*(3), 273–283.

O'Donnell, M., Parker, G., Proberts, M., Matthews, R., Fisher, D., Johnson, B., & Hadzi-Pavlovic, D. (1999). A study of client-focused case management and consumer advocacy: The Community and Consumer Service Project. *Australian and New Zealand Journal of Psychiatry, 33,* 684–693.

Oliver, S. Clark-Jones, L., Rees, R., Milne, R., Buchanan, P., Gyte, G., et al. (2004). Involving consumers in research and development agenda setting for the NHS: Developing an evidence-based approach. *Health Technology Assessment, 8*(15), 1–142.

Olsen, K. (2001). Distributive justice and the politics of difference. *Critical Horizons, 2*(1), 5–32.

Padgett, D. K., Gulcur, L., & Tsemberis, S. (2006). Housing first services for people who are homeless with co-occurring serious mental illness and substance abuse. *Research on Social Work Practice, 16*(1), 74–83.

PATH Consumer Involvement Workgroup (2006). *Consumer practitioners in PATH-funded programs: Report of the Consumer Involvement Workgroup.* Retrieved January 8, 2007, from http://www.pathprogram.samhsa.gov

Paulson, R., Herinckx, H., Demmler, J., Clarke, G., Cutler, D., & Birecree, E. (1999). Comparing practice patterns of consumer and non-consumer mental health service providers. *Community Mental Health Journal, 35*(3), 251–269.

Pennington, L. H., & McMullin, L. (2004). *Consumer perspectives on issues confronting mothers in the SAMHSA Homeless Families Program.* Presented at the annual meeting of the American Public Health Association, Washington, DC.

People to End Homelessness (2006). Retrieved December 1, 2006, from. http://www.projo.com/news/content/projo_20050517_homelss17.2316c69.html

Picture the Homeless. (2006). Retrieved December 1, 2006, from http://foundationcenter.org/newyork/spotlight/ny_spotlight_040105.html

Podymow, T., Turnbull, J., Coyle, D., Yetisir, E., & Wells, G. (2006). Shelter-based managed alcohol administration to chronically homeless people addicted to alcohol. *Canadian Medical Association Journal, 174*(1), 45–9.

Powell, T., Yeaton, W., Hill, E., & Silk, K. (2001). Predictors of psychosocial outcomes for patients with mood disorders: The effects of self-help group participation. *Psychiatric Rehabilitation Journal, 25,* 3–11.

Prochaska, J. O., & DiClemente, C. C. (1992). In search of how people change: Applications to addictive behaviors. *American Psychologist, 47,* 1102.

Raiff, N. R. (1984). Some health related outcomes of self-help participation: Recovery, Inc. as a case example of a self-help organization in mental health. In A. Gartner & F. Reissman (Eds.), *The Self-Help Revolution* (pp. 183–193). New York: Human Sciences Press,

Roberts, L., & Rappaport, J. (1989). *Empowerment in the mutual help context: An empirical analysis of the value of helping others.* Lansing, MI: Authors.

Rappaport, J. (1993). Narrative studies, personal stories, and identity transformation in the mutual help context. *Journal of Applied Behavioral Science, 29,* 239–256.

Rappaport, J., Seidman, E., Toro, P. A., McFadden, L. S., Reischl, T. M., Roberts, L. J., et al. (1985). Collaborative research with a mutual help organization. *Social Policy, 15,* 12–24.

Ridgway, P., & Press, A. N. (2004). An instrument to assess the recovery and resiliency orientation of community mental health programs: The Recovery Enhancing Environment Measure (REE). In *Tools in development*, *NASMHPD/NTAC e-Report on Recovery*, Retrieved June 18, 2007, from http://www.namiscc.org/Recovery/2005/MeasuringRecovery.htm

Rosenheck, R. (2006, October 26). *Evaluating the chronic homeless "housing first" initiative.* Paper presented at Final Meeting of ICH Chronic Homeless Initiative, Rockville MD.

Rosenheck, R., Kasprow, W., Frisman, L., & Liu-Mares, W. (2003). Cost-effectiveness of supported housing for homeless persons with mental illness. *Archives of General Psychiatry, 60,* 940–951.

Rowe, M. (2007, March 1). Commentary presented at the 2007 National Symposium on Homelessness Research, Washington, DC.

Rowe, M., Hogue, M. A., & Fisk, D. (1996). Critical issues in serving people who are homeless and mentally ill. *Administration and Policy in Mental Health, 23,* 555–565.

Sabin, J. E., & Daniels, N. (1999). Public-sector managed behavioral health care: III. Meaningful consumer and family participation. *Psychiatric Services, 50*(7), 883–885.

Sabin, J. E., & Daniels N. (2001). Strengthening the consumer voice in managed care: I. Can the private sector meet the public-sector demand? *Psychiatric Services, 52*(4), 461–464.

Sabin, J. E., & Daniels, N. (2003). Strengthening the consumer voice in managed care: VII. The Georgia Peer Specialist program. *Psychiatric Services, 54*(4), 497–498.

Sackett, D. L., Straus, S. E., Richardson, W. S., Rosenberg, W., & Haynes, R. B. (2000). *Evidence based medicine: How to practice and teach EBM* (2nd ed.). London: Churchill Livingstone.

Salzer, M. S. (1997). Consumer empowerment in mental health organizations: Concept, benefits, and impediments. *Administration and Policy in Mental Health, 24*(5), 425–434.

Sanderson, I. (2004) Getting evidence into practice: Perspectives on rationality. *Evaluation, 10*(3), 366–379.

Segal, S. P., & Silverman, C. (2002). Determinants of client outcomes in self-help agencies. *Psychiatric Services, 53*(3) ,304–309.

Segal, S. P., Silverman C., & Temkin. T. (1995). Characteristics and service use of long-term members of self-help agencies for mental health clients. *Psychiatric Services, 46,* 269–274.

Sells, D., Davidson, L., Jewell, C., Falzer, P., & Rowe, M. (2006). The treatment relationship in regular and peer-based case management for clients with severe mental illness. *Psychiatric Services, 57,* 1179–1184.

Sen, A. (1999). *Development as freedom.* New York, Anchor.

Shern, D. L., Tsemberis, S., Anthony, W., Lovell, A. M., Richmond, L., Felton, C. J., et al. (2000). Serving street-dwelling individuals with psychiatric disabilities: Outcomes of a psychiatric rehabilitation clinical trial. *American Journal of Public Health, 90* (12), 1873–1878.

Shih, M. (2004). Positive stigma: Examining resilience and empowerment in overcoming stigma. *Annals of the American Academy of Political and Social Science, 591,* 175–185.

Siegel, C., Samuels, J., Tang, D., Berg, I., Jones, K., & Hopper, K. (2006). Tenant outcomes in supported housing and community residences in New York City. *Psychiatric Services, 57,* 982–991.

Silverstein, R., & Jensen, A. (2004, April). *Talking points: Social Security Advisory Board discussion on disability definition.* Retrieved January 6, 2007, from. http://www.ssab.gov/DisabilityForum/Silverstein%20talking%20points.pdf

Solomon, P. (2004). Peer support/peer provided services—underlying processes, benefits, and critical ingredients. *Psychiatric Rehabilitation Journal, 27*(4), 392–401.

Solomon, P., & Draine, J. (1995). The efficacy of a consumer case management team: Two-year outcomes of a randomized trial. *Journal of Mental Health Administration, 22,* 135–146.

Solomon, P., & Draine, J. (2001). The state of knowledge of the effectiveness of consumer provided services. *Psychiatric Rehabilitation Journal, 25*(1), 20–27.

Solutions at Work. (2006). Retrieved from http://www.solutionsatwork.org/

Stainbrook, K., Breidster, R., Heller, L., & Hornik, J. (2004). *Stories from homeless mothers on their struggles for public and private assistance* (pp. 1–37). Albany, NY: Advocates for Human Potential.

Stefancic, A., & Tsemberis, S. (in press). Housing first for long-term shelter dwellers with psychiatric disabilities in a suburban county: A four-year outcome study of housing access and retention. *Journal of Primary Prevention.*

Stone, M. (2006). Housing affordability: One-third of a nation shelter poor. In R. Bratt, M. E. Stone, & C. Hartman (Eds.), *A right to housing: Foundation for a new social agenda* (pp. 38–60). Philadelphia: Temple University Press.

Substance Abuse and Mental Health Services Administration/Center for Mental Health Services. (2000). *Cooperative agreements to evaluate housing approaches for persons with serious mental illness, Publication/presentation policy.* Rockville, MD: Author.

Substance Abuse and Mental Health Services Administration. (2001). *Guidance for applicants, Homeless Families Program - Phase II, 2001.* Rockville, MD: Author.

Substance Abuse and Mental Health Services Administration/Center for Mental Health Services. (2002). *Cooperative agreements to evaluate programs serving homeless families (women with psychiatric, substance abuse, or co-occurring disorders and their dependent children), Publication/presentation policy.* Rockville, MD: Author.

Substance Abuse and Mental Health Services Administration. (2005a). *Guidelines for consumer and family participation.* Rockville, MD: Author.

Substance Abuse and Mental Health Services Administration. (2005b). *Guidelines for assessing cultural competence*. Rockville, MD: Author.

Substance Abuse and Mental Health Services Administration. (2005c). *Transforming mental health care in America—Federal action agenda 2005*. Retrieved from http://www.samhsa.gov/Federalactionagenda/NFC_execsum.aspx

Tanenbaum, S. J. (2005). Evidence-based practice as mental health policy: Three controversies and a caveat. *Health Affairs,* 24(1), 163–173.

Tanzman, B. (1993). An overview of surveys of mental health consumers' preferences for housing and support services. *Hospital and Community Psychiatry, 44,* 450–455.

Teague, G., Johnsen, M., Rogers, J., & Schell, B. (2006, February 12–14). *Research on consumer operated service programs: Effectiveness findings and policy implications of a large multi-site study.* Presented at NASMHPD Research Institute 16th Annual Conference on State Mental Health Agency Services Research, Program Evaluation and Policy, Research to Inform the System Transformation Process, Baltimore, MD.

Trainor, J., Shepherd, M., Boydell, K. M., Leff A., & Crawford, E. (1997). Beyond the service paradigm: The impact and implications of consumer/survivor initiatives. *Psychiatric Rehabilitation Journal, 21,* 132–140.

Trainor, J., & Tremblay, J. (1992). Consumer/survivor businesses in Ontario: Challenging the rehabilitation model. *Canadian Journal of Community Mental Health, 11*(2), 65–71.

Tripp, J. (2004) *Consumer involvement in HIMS planning and implementation. Creating the vision to make it happen.* Presented at the Missouri Association of Social Welfare/HMIS Conference.

Tripp, J. (2005). *Benefits and methods of implementing consumer involvement in HMIS.* Presented at the Maine State HMIS Site Assessment Community Discussion Process.

Tripp, J., Freeman, K. et al. 2005). *The benefit of consumer involvement in Homeless Management Information Systems* [PATH National Teleconference]. Retrieved July 17, 2006, from http://www.pathprogram.samhsa.gov/text_only/tech_assist/Transcripts/BenefitConsumerInvolvement_7_2005.asp

Tsemberis, S. (1999). From streets to homes: An innovative approach to supported housing for homeless individuals with psychiatric disabilities. *Journal of Community Psychology, 27,* 225–241.

Tsemberis, S., & Asmussen, S. (1999). From streets to homes: The pathways to housing consumer advocacy supported housing model. *Alcoholism Treatment Quarterly,* 17(1), 113–131.

Tsemberis, S., & Eisenberg, R. F. (2000). Pathways to Housing: Supported housing for street-dwelling homeless individuals with psychiatric disabilities. *Psychiatric Services, 51*(4), 487–493.

Tsemberis, S., & Fischer, S. *Stable housing and consumer choice improve mental health: A four-year follow-up on housing first*. Manuscript in preparation.

Tsemberis, S., Gulcur, L., & Nakae, M. (2004). Housing first, consumer choice, and harm reduction for homeless individuals with a dual diagnosis. *American Journal of Public Health, 94,* 651–656.

Tsemberis, S. J., Moran, L., Shinn, M., Asmussen, S. M., & Shern, D. L. (2003). Consumer preference programs for individuals who are homeless and have psychiatric disabilities: A drop-in center and a supported housing program. *American Journal of Community Psychology, 32*(3/4), 305–317.

Tsemberis, S. J., & O'Callaghan, S. (2004). Harm reduction. In D. Levinson (Ed.), *Encyclopedia of homelessness* (Vol. 1, pp. 189–193). Thousand Oaks: Sage.

U.S. Department of Veterans Affairs. (2005). *MIRECC recovery resources*. Retrieved June 15, 2006, from http://www.mirecc.org/conferences/rehab-and-recovery/murphy/murphy.shtml

Van Tosh, L., Finkle, M., Hartman, B., Lewis, C., Plumlee, L. A., & Susko, M. A. (1993). *Working for a change: Employment of consumers/survivors in the design and provision of services for persons who are homeless and mentally disabled.* Rockville, MD: Center for Mental Health Services.

Viswanathan, M., Ammerman, A., Eng, E., Gartlehner, G., Lohr, K. N., Griffith, D., et al. (RTI—University of North Carolina Evidence-based Practice Center). (2004, July). *Community-based participatory research: Assessing the evidence* (Evidence Report/Technology Assessment No. 99; AHRQ Publication 04-E022-2). Rockville, MD: Agency for Healthcare Research and Quality.

Wang, C. C. (2003). Using Photovoice as a participatory assessment and issue selection tool: A case study with the homeless in Ann Arbor. In M. Minkler & N. Wallerstein (Eds.), *Community based participatory research for health* (pp. 179–200). San Francisco: Wiley.

Wells, K. B., Staunton, A., Norris, K. C., Bluthenthal, R., Chung, B., Gelberg, L., et al. (2006). Building an academic-community partnered network for clinical services research: The Community Health Improvement Collaborative (CHIC). *Ethnicity and Disease, 16*, S1.3–S1.17.

White, H., Whelan, C., Barnes, J. D., & Baskerville, B. (2003) Survey of consumer and non-consumer mental health service providers on assertive community treatment teams in Ontario. *Community Mental Health Journal, 39*(3), 265–276.

White, P. (2005). *How the Immaculate Shelter transformed from a shelter to a housing first program.* Presented at the annual meeting of the National Alliance to End Homelessness, Washington DC.

White, W. (2004, March 22–23). *The history and future of peer-based addiction recovery support services.* Prepared for the SAMHSA Consumer and Family Direction Initiative 2004 Summit, Washington, DC. Retrieved January 3, 2007, from http://www.bhrm.org/P-BRSSConcPaper.pdf

White, W. (1998). Slaying the dragon: The history of addiction treatment and recovery in America. Bloomington, IL: Chestnut Health Systems.

Wilson, W. J. (1996). *When work disappears.* New York: Knopf.

Yanos, P. T., Barrow, S. M., & Tsemberis, S. (2004). Community integration in the early phase of housing among homeless persons diagnosed with severe mental illness: Successes and challenges. *Community Mental Health Journal*, *40*(2), 133–150.

Yanos, P. T., Primavera, L., & Knight, E. L. (2001). Consumer-run service participation, recovery of social functioning, and the mediating role of psychological factors. *Psychiatric Services, 52,* 493–501.

Young, A., Chinman, M., Forquer, S., Knight, E. L., Vogel, H., Miller, A., et al. (2005). Use of a consumer-led intervention to improve provider competencies. *Psychiatric Services, 56,* 967–975.

Zimmerman, M. A., Reischl, T. M., Seidman, E., Rappaport, J., Toro, P. A., & Salem D. A. (1991). Expansion strategies of a mutual help organization. *American Journal of Community Psychology, 19,* 251–278.