



# **Mental Health Recovery: What Helps and What Hinders?**

**A National Research Project for the  
Development of Recovery Facilitating  
System Performance Indicators**

**October 2002**

*Prepared by:*

Steven J. Onken, Ph.D., Jeanne M. Dumont, Ph.D.; Co-Principal Investigators  
Priscilla Ridgway, M.S.W., A.B.D., Douglas H. Dornan, M.S.,  
Ruth O. Ralph, Ph.D.; Co-Investigators

*Prepared for:*

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A National Research Project for the Development of Recovery Facilitating  
System Performance Indicators**

**Phase One Research Report:  
A National Study of Consumer Perspectives on  
What Helps and Hinders Recovery**

**Research Team**

Steven J. Onken, Ph.D., Jeanne Dumont, Ph.D.; Co-Principal Investigators  
Priscilla Ridgway, M.S.W., Douglas H. Dornan, M.S.,  
Ruth O. Ralph, Ph.D.; Co-Investigators

**State Mental Health Agency Research Partners**

Arizona Department of Health Services, Division of Behavioral Health Services  
Colorado Mental Health Services  
New York State Office of Mental Health  
Oklahoma Department of Mental Health and Substance Abuse Services  
Rhode Island Department of Mental Health/ Mental Retardation  
South Carolina Department of Mental Health  
Texas Department of Mental Health and Mental Retardation  
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*The findings, discussion, and implications herein do not necessarily reflect the positions or policies of any of the project sponsors and State Mental Health Agency research partners. This report is based on the cumulative perspectives of the 115 focus group participants as analyzed and interpreted by the five-member research team.*

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—Steven Onken, Jeanne Dumont, Doug Dornan, Priscilla Ridgway, and Ruth Ralph  
*The Recovery Facilitating System Performance Indicator Research Team*

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*—Kevin Ann Huckshorn, R.N., M.S.N., I.C.A.D.C., Director,  
NASMHPD Office of Technical Assistance*

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## Executive Summary

*Mental Health Recovery: What Helps and What Hinders? A National Research Project for the Development of Recovery Facilitating System Performance Indicators* evolved from collaborative efforts among a number of State Mental Health Agencies (SMHAs). These states were interested in developing a measure related to recovery as one of a set of indicators that can be used to assess the performance of state and local mental health systems and providers. The specific aims of this project were to:

- ◆ increase knowledge about what facilitates or hinders recovery from psychiatric disabilities;
- ◆ devise a core set of systems-level indicators that measure critical elements and processes of a recovery-facilitating environment; and
- ◆ integrate items that assess recovery-orientation into a multi-state "report card" of mental health system performance measures, in order to generate comparable data across state and local mental health systems and encourage the evolution of recovery-oriented systems.

This Phase One Report describes the findings of the first specific aim of the project. Structured focus groups and qualitative research methods were used with a diverse cross-section of consumer/survivors. Ten groups were held in nine states to gain knowledge on what helps and what hinders mental health recovery. All concepts and findings are based, to the maximum degree possible, on the audiotaped words of participants. The five-person research team, each with significant recovery research experience, posited at the outset five important domains of recovery: resources/basic needs, choices/self-determination, independence, interdependence/connectiveness, and hope. Themes and data encompassing mental health services staff and the mental health system as a whole were also analyzed. Research participants, N=115, comprised a purposive sample that encouraged diversity. Thus, we systematically elicited insight and knowledge on mental health recovery from a diverse and broad base of consumer/survivors across the nation.

The research team used a process of qualitative coding, codebook development, cross coding, and recoding to develop a single set of findings across all of the groups. After coding each unique response, we compiled the responses thematically, first according to questions and second according to emergent themes. These themes include the domains and other emergent themes: basic material resources, self/whole person, hope/sense of meaning and purpose, choice, independence, social relationship, meaningful activities, peer support, formal services, and formal service staff.

While recovery is a deeply personal journey, there are many commonalities in people's experiences and opinions. The findings we present are comprehensive. We had to work hard

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to reduce the 1,000 pages of transcript data to a manageable set of themes, and some of the richness, nuance, and personal stories unfortunately are lost in the data reduction processes. In fact, recovery is facilitated or impeded through the dynamic interplay of many forces that are complex, synergistic, and linked.

A conceptual paradigm for organizing and interpreting the phenomenon of mental health recovery is beginning to emerge from the study findings. Recovery is a product of dynamic interaction among characteristics of the individual (the self/whole person, hope/sense of meaning and purpose), characteristics of the environment (basic material resources, social relationships, meaningful activities, peer support, formal services, formal service staff), and the characteristics of the exchange (hope, choice/empowerment, independence/interdependence).

Within this ecological context, basic material resources—a livable income, safe and decent housing, healthcare, transportation, a means of communication (e.g., telephone)—move people toward recovery. Poverty and the lack of basic resources undermine a sense of safety and hold people back in their recovery.

Concurrent with basic material needs, people need opportunities and supports to engage in the responsibilities and benefits of citizenship, of membership to community. Recovery involves a social dimension—a core of active, interdependent social relationships—being connected through families, friends, peers, neighbors, and colleagues in mutually supportive and beneficial ways. Social and personal isolation, poverty, emotional withdrawal, controlling relationships, poor social skills, immigrant status, disabling health and mental health conditions, past trauma, and social stigma impede the recovery journey.

Full citizenship expands beyond social relationships, however. Participants indicated that recovery is enhanced through engaging in meaningful activities that connect one to the community. Often this can be achieved through a meaningful job and career, which can provide a sense of identity and mastery. Participants also identified other options, such as advancing one's education, volunteering, engaging in group advocacy efforts, and/or being involved in program design and policy level decision-making. Participants report high rates of unemployment, underemployment, and exploitation. Training and education opportunities are lacking, benefits have employment disincentives, prejudice and discrimination hamper efforts, and individual wishes and decisions are disregarded.

When considering both the basic material needs and citizenship dimensions to recovery, we are struck by how generic and universal the responses were. Just like any group of American adults, the responses included a compelling belief in the “American Dream” of economic opportunity, self-sufficiency, liberty, and the pursuit of happiness.

Our findings support personhood serving as another critical dimension of recovery. Participants talked about the internal sense of self, inner strivings and their whole being (physical, emotional, mental, and spiritual) as affected by and affecting the recovery process.

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They described various personal qualities, attitudes, and conditions that can help (self-reliance, personal resourcefulness, self-care, self-determination, self-advocacy, holistic view) or hinder (not taking personal responsibility, shame, fear, self-loathing, invalidation, disabling health and mental conditions).

The personhood dimension is also about hope, purpose, faith, expectancy, respect and creating meaning. Participants described how developing a sense of meaning, purpose and spirituality as well as having goals, options, role models, friends, optimism, and positive personal experiences support recovery. Demeaned dreams, pessimistic staff, poor quality services, discounted spirituality, poverty, unwanted and long-term psychiatric hospitalization, and lack of education and information about one's condition and potential resources destroy hope and act as roadblocks to recovery. All have powerful negative effects on individuals' self-concept, esteem, and sense of efficacy. These effects are compounded by mental disorder itself and the associated stigma (internalized and external), prejudice and discrimination.

Believing that recovery is possible and having this belief supported by others (friends, family, peers, and staff) helps fuel self-agency (the process of intentionally living one's life on one's own accord). Participants want to understand what they are experiencing, they want to be educated, have good information and actively participate in making important choices. It is also important to note that some of our findings seem to indicate that certain cultural affiliations, such as tribal community, may modify the emphasis on self-agency through activating kinship or tribal mores that stress interdependency or living for the good of the larger social unit.

When considering the fullness of the personhood and self-agency dimension to recovery, we are again struck by how such findings speak to universal quality of life needs and desires. Participants' life journeys began prior to the onset of mental illness and continue after. Hope advances many participants' life journeys. Thus, a holistic focus and positive expectancy (regarding attitudes, beliefs, and goals) on one's own part, on the part of helpers, within families, and in the media and the broader community can move recovery forward.

Empowerment is another critical dimension of recovery. The goal of empowerment becomes one of people gaining power and control over their lives through access to meaningful choices and the resources to implement those choices. Our findings document the crucial role that choice plays in empowerment. Having information on, and access to, a range of meaningful and useful choices and options fosters recovery. Participants are empowered when they make the choices regarding where they live, housing, finances, employment, personal living/daily routine, disclosure, who they associate with, self management and treatment. Individual participants talked about the empowering experience of choosing "how I see myself, my disorder, my situation, my quality of life." But for such empowerment to occur, meaningful options must exist and people must have training and support in making choices, and the freedom to take risks and fail. Too often quality of life choices seemed outside the realistic reach of many participants. Options are limited, lousy, or nonexistent.



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Participants recounted service providers, professional and family members and communities that responded through the use of coercion, control, restricted access or involvement, discrimination, and stigmatization.

Independence (not being subject to the control of others, and not requiring or relying on others—*Webster's II New Riverside University Dictionary*, 1984) also falls within the empowerment dimension. Participants expressed it as both a process and goal of recovery. Independence is achieved through making one's own choices and decisions, exercising self-determination (such as advanced directives), enjoying basic civil and human rights and freedom, and having a livable income, a car, affordable housing, etc. Paternalistic responses, lack of respect, involuntary and long-term hospitalizations, stereotyping, labeling, discrimination, the risk of losing what benefits and supports one does have, all undermine independence. Repeated encounters with such experiences instill fear, lack of confidence, and negative attitudes and beliefs.

Some participants talked of the importance of both independence and interdependence, reaching beyond the goal of independence to that of embracing interdependence. Interdependence is a term that implies an interconnection or an interrelationship between two entities and is used to describe the link of people to people. Seeking independence and seeking interdependence are not mutually exclusive.

The mental health self-help and consumer/survivor movement provides referent power opportunities. The need for a large-scale expansion, funding, support and availability of peer services, such as peer support, education, outreach, role models, mentors, and advocates was a common theme across all focus groups. Participants identified the need for alternative services and “experienced experts/peer specialists” employed across all levels of mental health service provision. Limitations in funding, geographical availability, participation, and leadership development opportunities, as well as lack of transportation, and controlling and mistrustful professionals hinder peer support efforts.

The formal service system, and the professionals and staff employed within it, constitute another dimension that impacts recovery. We clearly see that progress toward recovery can be supported through the formal system. There was, however, much more “hindering” content within our data regarding formal systems than any other domain.

We must fully acknowledge that the formal system often hinders recovery through bureaucratic program guidelines, limited access to services and supports, abusive practices, poor quality services, negative messages, lack of “best practice” program elements, and a narrow focus on a bio-psychiatric orientation that can actually serve to discount the person's humanity and ignore other practical, psychological, social, and spiritual human needs. At the core of such hindering forces is the operationalization of society's response to mental illness, that of shame and hopelessness and the need to assert social control over the unknown and uncomfortable.

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Many of our findings lend further support to shortcomings already identified within the formal system of care. Often these hindering influences are the unintentional consequences of procedures implemented by well-meaning authorities in a belief that the practices are in the best interest of patients. People have basic subsistence needs that “the safety net” does not meet. Social welfare and mental health programs are fragmented and difficult to access. People do not want to have to deteriorate in order to receive help, nor do they want to lose vital supports when they make progress toward recovery. Psychiatric services can be experienced as a means of social control, countering individual efforts of recovery.

The experience of trauma and abuse was also notable across the focus groups. The impact of the status of the mental health patient comes through in our findings—through the discussion of internalized stigma, the repeated traumatizations by the system, and the historical trauma of past abuse. The formal service system and many of its personnel largely overlook how responding to, and coping with, trauma is a central experience of psychiatric disorder and thus the system fails to incorporate trauma knowledge in existing explanations of, and responses to, mental illness. Pivotal in creating a culture of belonging, safety, openness, participation, citizenship, and empowerment is the large-scale support of peer services and peer staff, both independent of and integrated into existing service delivery systems.

Another critical change involves the need to return to the basic core of helping, a “therapeutic alliance”—the need for positive helping relationships based on partnership. People do not want to interact with neutral detached helpers, nor do they want to meet a new professional or paraprofessional each time they seek help. Opportunity for choice and negotiation in selecting partnership relationships with a doctor, therapist or case manager were strong concerns. People desire the collaborative development of individual treatment plans with full information on the potential benefits and side effects of medication. Most people sought to continue to be in charge of her or his treatment or recovery plan to the maximum degree possible and to exercise choice in all aspects of their lives, sometimes through the use of mental health care proxies or advance directives. They want to have people care for them and listen to them and empower them. Respect becomes critical. The whole focus of the helping relationship should have this value at its core—the actualization of the individual through self-determination and choice.

Recovery can be construed as a paradigm, an organizing construct that can guide the planning and implementation of services and supports with people with severe mental illness. The outlines of a new paradigm recovery-enhancing system are emerging. Such a system is person-oriented, and respects people’s lived experience and expertise. It promotes decision-making and self-responsibility. It addresses people’s needs holistically and contends with more than their symptoms. Such a system meets basic needs and addresses problems in living. It empowers people to move toward self-management of their condition. The orientation is one of hope with an emphasis on positive mental health and wellness. A recovery-oriented system assists people to connect through mutual self-help. It focuses on positive functioning in a variety of roles, and building or rebuilding positive relationships.

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The work of Phase One of this project constitutes a rich and complex fabric of findings for use in formulating future research, including the construction of evaluation tools to examine mental health system performance as to how well local and state mental health systems promote or facilitate mental health recovery. It is clear that the way we configure mental health and social service policies, formal mental health services and the day-to-day informal cultures that exist within programs and systems can serve to either promote or inhibit recovery. The following are key implications of the findings.

- ◆ Since persons are at the core of a dynamic interplay among themselves, other people, the resources available in the environment, and other forces, mental health services must recognize and allow for self-agency while bolstering, or at least not undermining, such efforts. Seeing people as whole persons beyond their labeled identity is integral to recovery.
- ◆ A shift to a recovery orientation will require attention to wellness and health promotion, not simply attention to symptom suppression or clinical concerns. Attention must be paid to basic needs in safe and affordable housing, health care, income, employment, education and social integration.
- ◆ A recovery orientation will require close attention to fundamental rights and needs. Re-orientation away from coercion requires alternative resources as well as training.
- ◆ There needs to be a continual evolution in our thinking, and for development of knowledge concerning recovery among diverse communities. For example, the balance of autonomy and self-reliance versus group or family focus may differ in recovery based on such factors as ethnicity and culture. Special attention is needed for people who have experienced trauma or who have substance use disorders.
- ◆ Resources for re-educating families, consumers, the professions and paraprofessional providers, young people, and the public at-large on the potential for recovery are called for, and will take significant investment. Stigma and misinformation must be countered through a variety of strategies (with attention to incorporating active roles for consumer/survivors) that target many audiences.
- ◆ Hope and empowerment are critical and their relationship to recovery warrants further research attention.
- ◆ True parity of decision-making power and respect through mutual and supportive partnership among consumer/survivors, professionals, administrators, and policy makers can become the basis of collaborative efforts to design and implement action strategies that will move America's mental health systems toward a recovery orientation.

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- ◆ Adequate resources are needed to fund and support consumer voice and consumer leadership development.

Several factors contributed to the limitations of this study. Recruitment limited representation of age, ethnic and cultural diversity. The recruitment process in all states entailed self-selection and is not fully representative of the population of public mental health system recipients. The size of the focus groups, which exceeded the optimal, may have somewhat limited individual participant opportunities to share insights and observations. Focus group methodology limits identification of consensus as well as the themes or domains that are most or least important.

The long-term goal of this research project is the development of a core set of systems-level indicators that measure critical elements and processes of a recovery-facilitating mental health service environment. In Phase Two of this work, the findings of Phase One will be utilized to comprise a set of prototype performance indicators. In Phase Three the resulting measure will be pilot-tested across multiple sites.

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## Introduction

The term “recovery” is used to acknowledge that people can successfully contend with severe and persistent psychiatric disorders, function well, and create positive lives. As such, recovery is a multi-faceted concept with a connotation that persons with disabling mental disorder and varying severity of disability can and do restore and/or generate to full human capacity. Recovery is grounded in resiliency—the complex dynamic internal and external processes that enable people to surmount crises and persistent stress and express their innate strengths, self-righting capacities, and hardiness (Ridgway, 2001; Ridgway, in preparation, a; Walsh, 1999). Recovery does not happen in a vacuum; relationships, external resources and environments play strong roles. This report explores the process of recovery and the dynamic interplay of factors that facilitate or impede recovery.

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- ◆ increase knowledge about what facilitates or hinders recovery from psychiatric disabilities,
- ◆ devise a core set of systems-level indicators that measure critical elements and processes of a recovery-facilitating environment, and
- ◆ integrate items that assess recovery-orientation into a multi-state "report card" of mental health system performance measures, in order to generate comparable data across state and local mental health systems and encourage the evolution of recovery-oriented systems.

## Background

The research described in this report grew out of the 16 State Indicators Project of the Mental Health Statistics Improvement Project (MHSIP). Several participating states sought to mount a recovery sub-study as a part of their grant proposal. A collaborative effort was initiated to avoid duplication of effort and build upon the efforts of people who had spent considerable energy and time defining and researching the concept of recovery and related areas. Those organizing the joint effort recognized that the application of recovery concepts to mental illness has grown largely out of the consumer/survivor movement. The organizers valued the critical role that consumer/survivor involvement plays in developing an understanding of recovery. Therefore, SMHA researchers and planners recruited and involved consumer and non-consumer researchers with significant expertise in recovery for the project.

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An initial work group convened in May 2000 in Austin, TX. The meeting was based in an “expert panel approach,” involving several people with a strong understanding of the recovery literature and research, those with experience in SMHA evaluation and planning, along with other interested SMHA participants and consumers. Participants reviewed recovery materials and research to inform the planning process. Through lively discussion, the group clarified that recovery is a personal journey and complex process that extends beyond the boundaries and influences of the mental health system. However, participants also recognized that mental health systems play important roles, and can both positively and negatively influence the personal process of recovery.

The work group explicitly rejected the idea of developing a standardized measure of individual recovery. The rationale for rejecting an individual measure of recovery approach included fear that a measurement model would evolve that would ultimately be used as a tool to cut-off access to public mental health services, and the belief that recovery is an individualized process rather than a standardized "state" to be attained. Participants decided against a proposed strategy of pulling individual items or indicators from existing measures of recovery or empowerment. No existing recovery measure had adequate psychometric testing. None were viewed as appropriate for adoption or adaptation at a systems level.

The group also examined existing definitions of recovery, concentrating on those offered by three participants. In her review of recovery literature, Ruth Ralph summarized that “recovery can be defined as a process of learning to approach each day’s challenges, overcome our disabilities, learn skills, live independently and contribute to society. This process is supported by those who believe in us and give us hope” (Ralph, 2000b, p. 22). Doug Dornan’s research led to a public health definition of recovery as “the act of gaining and taking back hope, personal identity and abilities—from loss due to disorder, injury or submission to powerlessness. It is also a taking back of trust in one’s own thoughts and choices so as to restore mental, emotional, social and biological order. Mental health recovery may be lifelong, intermittent or short-term” (Dornan, Felton, & Carpinello, 2000, p. 3). Ridgway’s examination of consumerist research and first person accounts of recovery yielded the following definition, “Recovery is an on-going journey of healing and transformation. It involves reclaiming hope and a positive sense of self despite the experience of psychiatric disability, self-managing one’s life and mental health to reduce psychiatric symptoms and achieve higher levels of wellness, and reclaiming a life and roles beyond being a consumer in the mental health system” (Ridgway, 1999).

Participants developed a working definition of mental health recovery that represented a synergist blending of the existing conceptualizations of recovery. Specifically, the group chose to define recovery as follows.

Recovery is an ongoing dynamic interactional process that occurs between a person’s strengths, vulnerabilities, resources and the environment. It involves a personal journey of actively self-managing psychiatric disorder while

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reclaiming, gaining and maintaining a positive sense of self, roles and life beyond the mental health system, in spite of the challenge of psychiatric disability. Recovery involves learning to approach each day's challenges, to overcome disabilities, to live independently and to contribute to society. Recovery is supported by a foundation based on hope, belief, personal power, respect, connections, and self-determination.

Participants used group methods to generate important domains of recovery. The domains included independence, self-efficacy, sovereignty, self-determination, resources, basic needs, competencies/abilities, interdependence, and connectiveness. The group brainstormed a rough set of items that might be useful in assessing the identified domains.

On subsequent conference calls, those involved reached consensus that the expert panel workshop approach was not enough. Participants felt that the published recovery research literature did not provide an adequate empirical underpinning for understanding the role that service environments play in facilitating or impeding personal recovery. Participants wanted more knowledge, and were dissatisfied with the results attained by brainstorming in the Austin meeting. The work group determined that there was a need for structured collection of grassroots consumer input regarding what they have found hinders and helps them achieve recovery in their lives. The data gathered would include, but not be limited to, information concerning what mental health systems and services do that tends to promote or hold back the personal process of recovery. Participants agreed that the broad domains of recovery that had been identified in Austin should serve as the basis of a set of open-ended standardized questions that would generate answers to the guiding question, "What helps and hinders recovery?" The group established a research team, selected from among the participants with the intent to conduct a consumer-driven research effort.

### **Statement of Assumptions**

The research team identified several assumptions to guide the inquiry.

- ◆ Recovery from mental disorder or psychiatric disability is an individual process that is, and must remain, based in self-agency.
- ◆ Recovery can best be understood through the lived experience of persons with psychiatric disabilities who are in the process of recovery.
- ◆ Inadequate knowledge exists on the lived experience of recovery and the factors and processes in the social and physical environment that help or hinder recovery.
- ◆ Recovery research should have significant consumer/survivor involvement at every stage, from research design, data collection and data analysis to interpretation and dissemination

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of findings. Research should be a partnership; consumers/survivors should not be treated merely as the objects of study. Recovery research processes should be empowering.

- ◆ Consumer/survivor involvement should extend beyond mere tokenism that has unfortunately characterized many efforts in the past. Consumer/survivor perspectives should be sought beyond those of a few "leading consumers." There is significant diversity of opinion on recovery and profound diversity within the population. Recovery paradigm thinking has evolved differently in various regions of the country; recovery means different things to consumers/survivors with differing standpoints, and at different stages of recovery. A national project must take into account and honor diverse perspectives.
- ◆ Formal services may or may not support or influence recovery. Some people recover without formal services; some people say they recover in spite of the anti-recovery influences of poor service systems; while others attribute recovery, at least in part, to mental health treatment, helping relationships, rehabilitation programs and community support services.
- ◆ An understanding that the roles formal helping systems play in recovery must be placed in the context of knowledge of self-agency and the many other contextual factors that may support or hinder recovery.
- ◆ Without fundamentally re-conceptualizing the relationship between individual consumers/survivors and the formal helping system, well-intended policy makers risk promulgating a cosmetic initiative of recovery that maintains the dependence of individuals on the mental health system.
- ◆ The critical nature of this undertaking demands scientific rigor in each step of the project. Conceptualization and research regarding mental health recovery is still in its infancy and there is significant disagreement. Performance indicators resulting from this project will only be as defensible as the underlying processes used to develop them. Strong efforts must be mounted to ensure scientific rigor throughout the course of the inquiry.

## **Research Plan**

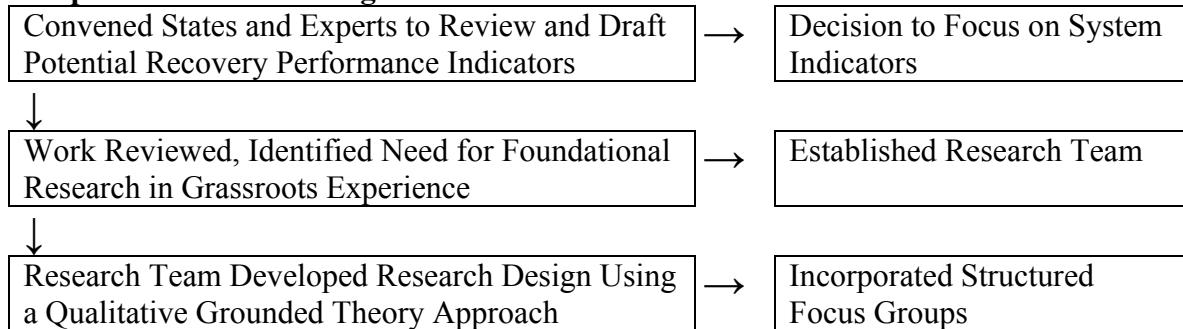
The work of the project is designed to unfold through three phases. The flowchart of the following page recaps the evolution of this research project through Phase One, the focus of this report.



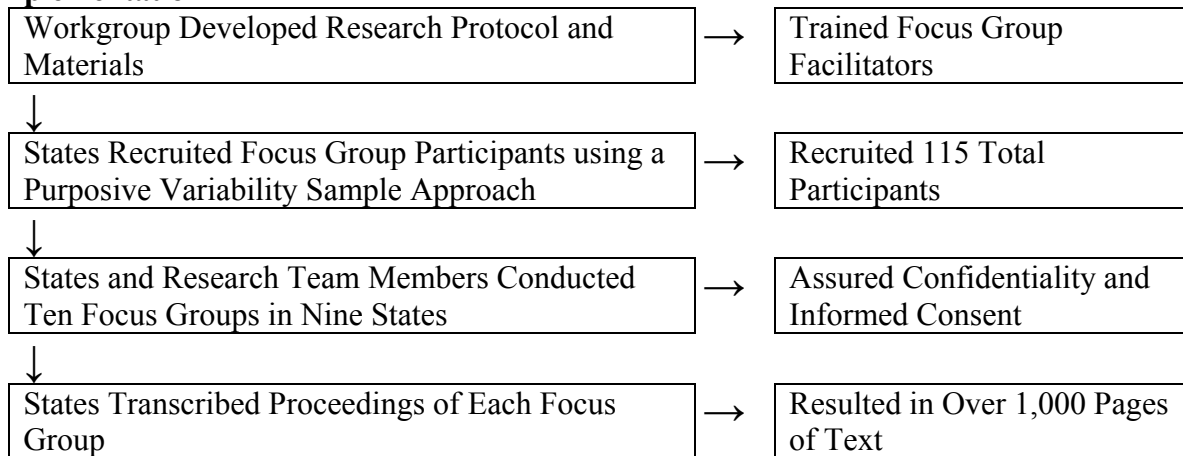
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## Flowchart of Evolution of Project Through Phase One

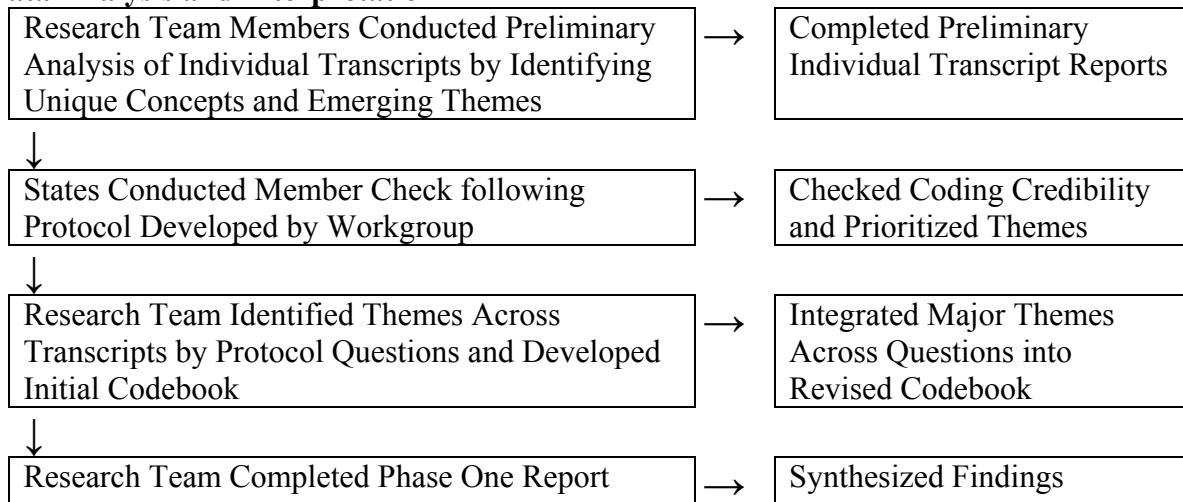
### Conceptualization and Design



### Implementation



### Data Analysis and Interpretation



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Phase One creates grounded theory concerning the phenomenon of recovery and the ways in which the social environment, including the mental health system, impact upon the process. In this phase, a qualitative research design is used to capture grassroots consumer/survivor experience concerning what they find that hinders or helps their ability to achieve recovery.

In Phase Two, the research team will create prototype systems-level performance indicators, derived from the Phase One results, which will assess important elements and processes within mental health systems that facilitate or hold back recovery.

In Phase Three, a recovery performance indicator measure will be pilot tested in participating states. Statistical analysis will be conducted on the data gathered to assess the psychometric properties of the measure.

The research plan utilizes grounded theory and applied findings concerning patterns found in recovery to build knowledge that can assist in the redesign of more effective systems of mental health/behavioral health care. Findings can be used to alter programmatic supports and interventions during this crucial period of transition in the field's thinking—as the mental health field moves toward a recovery orientation. The findings of this study can also be used to sensitize staff to the challenges and processes of recovery. The study builds on earlier studies of recovery, and will assist in the creation of a set of concepts, definitions, and dynamic propositions or theories of processes (Brewer & Hunter, 1989) useful in future qualitative and/or quantitative recovery research.

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## Literature Review

Recovery is receiving increasing attention throughout the mental health community for social, political and economic reasons (Ralph, 2000a). Consumers of mental health services who discover the recovery concept are given hope that they, too, can reach some level of normal life. Providers realize that to have their clients recover is to their advantage, not only because the people they serve can enjoy better mental health, but also because they can focus their resources of staff and time on assisting those who are most in need. Payers for mental health services (HMOs, Medicaid) are interested in being able to reduce services and costs. Funders of services (i.e. state mental health departments, federal programs, legislators) want to see their dollars produce success. Thus, recovery has become the latest “buzz word” in mental health circles. What recovery is, how it is defined, and how it is accomplished are the subject of many discussions, writings, and presentations.

### Definition of Recovery

The formal definition of the word recovery means “to get back: regain” or “to restore (oneself) to a normal state” (*Webster’s Dictionary*, 1984). The term recovery has been used extensively in the field of substance abuse where the concept of “recovery” means people go back to pre-drinking or pre-drugging lives.

The mental health consumer/survivor movement, which emerged in the early 1970s, gave voice to the notion of mental health recovery and the related emphasis on self-determination and empowerment. Though the term seldom appeared in the professional mental health literature until the late 1980s, it has been embedded in consumer writings, activities and research as early as the 1930s.

Recovery from mental illness can best be understood through the lived experience of persons with psychiatric disabilities. Ridgway (2001) analyzed four early consumer recovery narratives (Deegan, 1988; Leete, 1989; Lovejoy, 1982; Unzicker, 1989) with a constant comparative method to find common themes. These themes are listed below.

- ◆ Recovery is the reawakening of hope after despair.
- ◆ Recovery is breaking through denial and achieving understanding and acceptance.
- ◆ Recovery is moving from withdrawal to engagement and active participation in life.
- ◆ Recovery is active coping rather than passive adjustment.
- ◆ Recovery means no longer viewing oneself primarily as a mental patient and reclaiming a positive sense of self.
- ◆ Recovery is a journey from alienation to purpose.
- ◆ Recovery is a complex journey.
- ◆ Recovery is not accomplished alone—it involves support and partnership.

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In a review of recovery literature, Ralph (2000b) identified the following four dimensions of recovery found in personal accounts:

- ◆ internal factors: factors that are within the consumer, such as awareness of the toll the illness has taken, recognition of the need to change, insight as to how this change can begin, and the determination it takes to recover;
- ◆ self-managed care: an extension of the internal factors in which consumers describe how they manage their own mental health and how they cope with the difficulties and barriers they face;
- ◆ external factors: include interconnectedness with others, the supports provided by family, friends, and professionals, and having people who believe that they can cope with, and recover from, their mental illness; and
- ◆ empowerment: a combination of internal and external factors—where internal strengths are combined with interconnectedness to provide self-help, advocacy, and caring about what happens to ourselves and to others (Ralph, 2000b).

Consumer perspectives on recovery point to both diversity and commonalities in experience. Exploratory research on mental health recovery and recovery-related inquiries suggests emerging domains such as resources, self-determination, independence, connectiveness, and hope/optimism may contribute to the recovery of individuals (Campbell & Schraiber, 1989; Carpinello, Knight, & Jatulis, 1992; Dumont, 1993; Onken, 2000; Ralph, 2000b; Ridgway, 1999, 2001, & in preparation, a).

Concomitant with an interest in recovery is the attempt to measure it. Ralph, Kidder, and Phillips (2000) question the adequacy of various attempts that have been made to measure recovery noting that many efforts measure something about recovery rather than recovery per se, probably reflecting the state of the evolving concept. Little attention has been paid to the measurement of the environment facilitating recovery to date, although some work to create a valid and reliable measure of a recovery-facilitating environment is progressing (Ridgway, in preparation, b).

It has generally been acknowledged that the mental health system must provide an environment that stimulates and encourages recovery (Anthony, 1993). Just as recovery must be measured in its entirety, to include aspects such as anguish as well as the positive side of recovery (Ralph & Recovery Advisory Group, 1999), the breadth of the system's impact on recovery—its hindrances as well as its promotion—must be measured. It is important to understand the roles, both positive and negative, that formal helping systems and other environmental factors play in recovery.

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## Recovery of Mental Health and Change in Mental Health Systems

Anthony (1993) introduced recovery as the guiding vision for the mental health system after reading and listening to consumers' personal accounts of their struggle through, and recovery from, mental illness. He traces the progress of the mental health system from the era of deinstitutionalization through the establishment of community support and rehabilitation services, with recovery envisioned as the next step in the process of evolution. Anthony notes that deinstitutionalization focused on new uses for buildings and facilities, and the community support system was planned as a network of essential services to support persons with psychiatric disabilities, with the field of psychiatric rehabilitation emphasizing treating the consequences of mental illness. However, recovery speaks to how people who are recipients of service will live and choose the services they need and want. The mental health system must provide an environment that stimulates and encourages recovery (Anthony, 1993). Anthony (2001) recently published a set of suggested standards for a recovery-oriented service system.

Many mental health systems are now incorporating recovery into their state's planning initiatives (Emery, Glover, & Mazade, 1998). A number of states have included the word recovery or the concept of recovery in documents such as mission statements, guiding principles or descriptions of treatment programs. Some states are trying to incorporate recovery into the way mental health services are provided.

In a report prepared for the Wisconsin Blue Ribbon Commission on Mental Health Care, Jacobson (1998) reports the findings of semi-structured telephone interviews conducted with key staff in 12 states, asking about how they operationalized and implemented recovery in their state mental health system. Jacobson obtained her sample by identifying states that were purported to be leaders in this area, and was referred to others through a snowball sampling process. She indicated that states are at different stages in planning and implementation, and that approaches to incorporating recovery differ from state to state. "Some states seem to be repackaging their old service models (e.g., CSPs, supported education, rehabilitation services) using the recovery language; others are wholly re-inventing themselves" (p. 1).

In a summary of this study, Jacobson and Curtis (2000) describe the process taken by states to develop a "recovery-oriented" service system and the areas or strategies selected to do this. The process is described as an effort to understand the concept and to determine its viability and value within clinical and financial constraints. The development of a vision statement is often done through the establishment of a task force or work group that includes diverse stakeholders. Multiple sources of information are tapped to assist in the understanding of the concept and the development of a vision statement. These processes incorporate a working definition of recovery and make recommendations to implement the principles identified.

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With vision statements in hand, some states simply rename their existing programs: Community support services, vocational rehabilitation or housing support are now described as ‘recovery-oriented’ services. This renaming process demonstrates a lack of understanding of recovery; in particular, a failure to acknowledge the necessity for a fundamental shift toward sharing both power and responsibility (Jacobson & Curtis, 2000, p. 335).

Strategies to implement and operationalize recovery in the mental health system in those states that have moved beyond the service renaming stage include “education, consumer and family involvement, support for consumer operated services, emphasis on relapse prevention and management, incorporation of crisis planning and advance directives, innovations in contracting and financing mechanisms, definition and measurement of outcomes, review and revision of key policies, and stigma-reduction initiatives” (Jacobson & Curtis, 2000, p. 335).

In describing the implementation of a rehabilitation-recovery philosophy in the Illinois mental health system, Barton (1998) indicates that all of the disciplines involved in providing mental health services must collaborate with consumers, and with each other, to assist consumers in conceptualizing, setting, and reaching their recovery goals. Barton summarizes: “the consumer-centered recovery philosophy is the umbrella over all models, disciplines, practices, and activities in the hospital and the community” (p. 177). Barton also recognizes the need for professionals and policy-makers to re-examine, re-evaluate, and re-define their own professional identities and roles.

State and federal initiatives to identify successful mental health services include recovery as one of the areas that must be addressed. A draft report of work done by the National Association of State Mental Health Program Directors (NASMHPD) Technical Workgroup on Performance Indicators (1998) includes Recovery/Personhood/Hope as one of nearly 50 indicators for adults with serious mental illness. This indicator is identified as “developmental” in that there are no identified measures for this area as yet, but it is deemed important enough to be included, and work is needed to search for or develop means to measure this indicator.

In a survey of state offices of mental health about consumer involvement in state surveys, Kaufmann (1999) asked if the state included the concept of recovery within its consumer survey. Of the 49 states and territories that responded, 67% indicated that they did so. The majority of these states, however, indicated they defined recovery the same as the Mental Health Statistics Improvement Program (MHSIP) and used the outcome measures from the MHSIP Report Card as recovery measures. The Report Card was not developed as a measure of recovery, and is not considered an adequate measure of recovery.

State Indicator Pilot Grants were awarded by The Center for Mental Health Services (CMHS) to 16 states in 1998 to pilot 32 selected performance indicators incorporated from the CMHS Five State Feasibility Study and the NASMHPD Framework of Mental Health Performance

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Indicators. The study described in this report is an effort of a subgroup of these states to define indicators of recovery for mental health systems.

Jacobson and Curtis (2000) conclude their article on recovery and systems change with some very important and thought provoking questions about recovery and how, or whether, it should be incorporated into the mental health system. These comments are included in total here, because they speak to the major challenges that must be faced by individuals and systems as recovery is studied and programs and systems attempt to implement and operationalize a recovery orientation.

- ◆ How can we deepen our understanding of recovery as an individual process? What stimulates and sustains the process? What hinders or smothers it? What are the best methods for answering such questions?
- ◆ Can recovery be measured? Should recovery be measured? What are the risks of doing so? Of not doing so?
- ◆ How can we transfer our knowledge about recovery as an individual process to our policy-making and service planning activities? How do specific policies and services affect individual recovery?
- ◆ How will we know we are creating a recovery-oriented system? By what criteria should the system be judged? Should we measure individual gains? Aggregate outcomes? System-level change? Over what period of time?
- ◆ How can we balance recovery as an individual, singular process, with the system's need for standardization? Can we formulate a generalized concept of recovery and still respect the process as unique?
- ◆ For what should we hold the system accountable? Are we willing to trade off some system liability for the increased self-determination and personal responsibility that seem to be the hallmark of recovery?
- ◆ What barriers stand in the way of implementing a recovery orientation? What forces sustain the status quo?

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- ◆ *Should* recovery be the foundational principle of the mental health system?

These problems start with problems of epistemology—how best to study and measure recovery. But they end in problems of politics and values—what is to be our society’s approach to helping persons with psychiatric disabilities? For recovery to herald a real change in our assumptions and practices, and to make a difference in the lives of people living with severe and persistent mental illness, it is vital that all of these questions be engaged. How we choose to answer them will shape mental health services in the coming decades (Jacobson & Curtis, 2000, p. 339).

This study, *Mental Health Recovery: What Helps and What Hinders?*, begins to address the concerns raised by Jacobson and Curtis. It builds a broad empirical knowledge base on what stimulates and sustains personal recovery and what holds it back. It also captures consumer/survivor perspectives on what constitutes a recovery-oriented mental health system, expanding the early work of Trochim, Dumont, and Campbell (1993) that incorporated the perspectives of consumers/survivors in developing mental health outcomes. Ultimately, in the course of this project the research team will design and test indicators and measures for assessing the recovery orientation of local mental health systems.



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## Methodology

The research design evolved over time. The methods and rationale were developed in an iterative process that involved many teleconferences and e-mail exchanges between the research team, SMHAs representatives, and project sponsors. Given the limited resources and short timeframe for designing and completing the inquiry, the project must be viewed as a developmental effort to advance the measurement of recovery. This effort would not—and could not—result in a definitive measure of recovery. Many other initiatives will be needed to further refine and develop recovery knowledge. The core design was reviewed and discussed in a teleconference with all parties in October 2000. Some SMHAs had consumers review and provide feedback as well, but they did not recommend any major changes.

### Research Design

The processes of recovery are complex, multifaceted and little understood. In such circumstances, qualitative examination of dynamic processes, rather than quantitative analysis of discreet variables, is the appropriate research methodology to further understanding (Rutter, 1987). Simply put, not enough is known about the experience and life process of recovery. Therefore, this study is framed as exploratory, phenomenological research using principles of grounded theory (Glaser & Strauss, 1967). Such inquiry is begun without a priori hypotheses. By minimizing presupposition, the research team inductively builds empirical research knowledge that is grounded in an understanding of the day-to-day experience of people with psychiatric disabilities and their life world. The study is not atheoretical—an ecological perspective provides a broad meta-theoretical conceptual framework for the inquiry. This perspective views human behavior as contextual and a function of the dynamic transaction between the person and the social environment (Germain, 1991).

Simply put, not enough is known about the experience and life process of recovery. Therefore, phenomenology research helps frame this study. “Indigenous meanings” or lived experience, as described by participants, allow an “emic” or insider perspective on complex social processes when understanding about particular life worlds is limited (Gubrium & Holstein, 1997). Data is analyzed in a manner that allows unexpected finding or novel frameworks of understanding.

The project uses a structured focus group approach to capture consumer/survivor experiences and understandings. Building upon the work generated in the Austin meeting and articulated in earlier recovery research, the research team created questions to solicit consumer/survivor input within five domains: 1) resources/basic needs, 2) choices/self-determination, 3) independence/sovereignty, 4) interdependence/connectiveness, and (5) hope.

The question sets for the study were deliberately designed to avoid asking directly about the influence of mental health services and staff until general questions about the five domains

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were completed. The avoidance of questions framed in terms of the influence of mental health services and staff allowed unbiased identification of all factors that people felt helped or hindered recovery. The final two questions in the question set were asked to insure that the influences of mental health services and staff were adequately captured (to the extent that participants did not address the influence of the mental health system within the context of the first five question sets). The specific questions asked in each focus group are listed below.

**Question Set #1:**

What resources are important to you to have control in your life?

What helps you get these resources?

What gets in the way of getting these resources?

**Question Set #2:**

What choices are important to you to have control in your life?

What helps expand your choices?

What stands in the way of having choices?

**Question Set #3:**

How do you, or what helps you, gain independence in your life?

What gets in the way of gaining independence in your life?

**Question Set #4:**

How do you, or what helps you, get connected and stay connected to other people?

What gets in the way of getting and staying connected to others?

**Question Set #5:**

How do you, or what helps you, gain hope in your life?

What gets in the way of gaining hope?

**Question Set #6:**

How have mental health staff and mental health services helped or hindered you in your life with gaining resources, choices, independence, connections with others, and hope?

**Question Set #7:**

If you were giving advice to the mental health decision makers in your state, what things would you tell them that they *or staff* could do to make your life better?

The research team developed a standardized focus group protocol that was reviewed by the SMHAs. Briefly stated, the protocol included the following items.

1. Each focus group was to have 8-15 mental health service recipients, who were paid an honorarium for participating.

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2. All focus groups were to follow the same format, using a prepared set of questions and a brainstorming approach, with all comments accepted and respected.
  3. Experienced facilitators were to be selected to lead the focus groups. At least one co-facilitator was to be a mental health consumer.
  4. The focus group facilitators were to participate in a conference call in order to prepare for conducting the focus groups. The call reviewed the protocol, went over the standardized approach to be taken, identified probes, anticipated and helped facilitators think through stumbling blocks, answered their questions, etc.
  5. Focus groups were to be audiotaped; consumer participants in the focus group were to be asked to sign a formal consent form to confirm participation and to signify their approval of being audiotaped.
  6. Tapes were to be transcribed by each state, with identifying information deleted. Hard copies and disk copies were to be made available for coding and abstracting by the research team.

A teleconference training and an extensive set of guidelines were provided to focus group facilitators. Thus all facilitators used an identical set of guiding questions and followed appropriate procedures for the focus group method (Krueger & Casey, 2000). Each focus group had co-facilitators, including at least one consumer. In six of the ten focus groups, a member of the research team served as a co-facilitator. The groups were tape-recorded and verbatim transcripts prepared (*Editor's note: A complete set of focus group materials is available in Appendix A*).

This study took advantage of the many strengths of qualitative inquiry (Maxwell, 1996): such work helps in understanding the meaning of events, situations and actions from the perspective of participants; it provides an understanding of the context in which people act; such research allows identification and description of unanticipated phenomenon; and increases understanding of the processes by which recovery takes place and the complex causal influences of the recovery process.

### **Sampling**

The research design incorporated a purposive sampling strategy. The research team worked with the nine participating SMHAs and encouraged them to attempt to recruit and engage a diverse group of participants. Specifically, the research team asked participating states to recruit focus group participants: 1) from different areas within the state (urban, rural, suburban); 2) who had differing service utilization patterns (some who did, and some who did not use public services); 3) to draw from differing demographic populations (diverse ethnicity/race, gender, age, diagnosis, etc.); and 4) to attempt to involve people who were at

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different stages of awareness and involvement in recovery and participation in the consumer/survivor movement.

Participants were recruited by the participating SMHAs using several means. Often the state director of mental health consumer affairs (or equivalent position) and/or the state level consumer organization were actively involved in the recruitment of the focus group participants and largely drew on their existing networks. Other recruitment efforts were more formal and attempted to select participants based on criteria that would assure diversity in representation. For example, New York recruited for two focus groups using flyers and posters that were mailed or faxed to all peer-run and community support programs in the two geographic areas, based upon mailing lists provided by statewide and local organizations. Tear-off sheets were included for potential candidates to respond with general demographic data that included whether they were from urban and rural locations, their education level, Medicaid status, and personal ratings of service utilization patterns and involvement in consumer-organized activities. Some local leaders also made individual contacts with potential participants. The optimal goal in the sampling was diversity rather than randomization. In New York, the applicant pool was stratified to include persons reflecting a wide set of characteristics using a grid that was constructed to ensure maximal diversity across the descriptors.

### **Human Subjects Protection and Data Handling**

Each state followed policies and procedures within their respective state for research and evaluation activities and administering informed consent. Participation was voluntary. For example, in New York, Phase One of the project was reviewed and approved by the Office of Mental Health New York State Central Office IRB on February 27, 2001. Application for an updated review was submitted and approved February 22, 2002.

In addition, the focus group protocol required all participants to be fully informed of the purpose of the study, its demands, their rights as informants and the risks and benefits associated with participation. The focus group facilitator training reviewed the consent process and the focus group materials included a script for seeking consent and an example consent form. Nominal stipends were provided to all those who attended regardless of amount or duration of participation. In addition, transportation costs and refreshments were provided for all participants. Transcripts were altered to remove participant names and other identifying information. All information was collected, stored, analyzed and reported in a manner that protected participants' anonymity, privacy and integrity.

### **Data Collection**

Data collection occurred February through April 2001 with ten focus groups held in nine states involving 115 participants. Initial feedback from the states indicated that all focus groups were conducted according to the protocol. Unfortunately the transcripts revealed that

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Question Set #3 was inadvertently skipped in one of the 10 focus groups and Question Set #7 in another.

Participants were highly engaged in the focus groups, and contributed extensive data that were viewed as extremely useful by participating states. Participant feedback indicates that the process of "grassroots" involvement in knowledge-building was very much appreciated. Several participants suggested that ongoing group processes should be mounted for mutual learning, staff development and policy planning. Some participants expressed skepticism that the knowledge they provided would lead to bona fide change in programs or systems. All participants were invited to participate in a follow-up "member check" that would provide the research team with feedback on whether the themes developed from the transcripts accurately captured their experience and thoughts.

### **Data Analysis**

Raw data included verbatim transcripts of focus groups, written comments provided by participants, and written facilitator notes that primarily concerned the group process. The research team coded the data. The data collected from each focus group underwent structured content analysis. Coders notated commonalities, disagreement and gaps within the data, and inductively created an evolving set of critical concepts. Each of the coders reviewed and organized the data into themes (i.e. higher order concepts) for each transcript. Coders then produced a preliminary report for each transcript that incorporated the focus group question sets and themes for that transcript. The research team met and created a common set of concepts and themes that pooled the findings across all focus groups under the domains of the question sets.

More specifically, analysis of data focused on the creation of grounded theory (Glaser & Strauss, 1967). Data analysis entailed several steps: 1) immersion in the data through multiple readings; 2) manual coding that began by breaking down the texts into segments or units of meaning; 3) structured content analysis and notation of commonalities, disagreement and gaps within the data; and 4) the inductive creation of an evolving set of critical concepts and interpretive themes. Continued testing of preliminary themes and concepts occurred against new raw data, until saturation occurred and no new thematic material was evidenced. Coding of the segmented texts was done using open coding techniques (Emerson, Fretz, & Shaw, 1995) so new findings from within and across transcripts could reconfigure preliminary coding categories. Analysis of patterns and clustering of data by theme was conducted using constant comparative methods (Lincoln & Guba, 1985). In this approach the initial themes were constantly tested against additional segments of raw data. Exemplary segments of focus group statements were identified that illustrated each theme.

When the transcripts of all 10 focus groups had been coded, the research team met face-to-face to develop an integrated set of themes that pooled concepts across all the focus group transcripts. Group process was used to work with the themes to integrate the findings and subsume them into larger conceptual categories. Working question-by-question, "round

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robin-style,” each member offered a theme from one of the ten preliminary reports that summarized themes by question for each transcript/focus group. The other team members then checked their reports for related themes and these were shared. A descriptor or series of descriptors were then agreed upon that captured the theme. Often research team members elaborated on excerpts from the transcript to clarify the meaning of a particular theme. Once named, the theme was noted and exemplary segments of focus group statements or meaning units related to the theme were recorded as “branches” of the theme.

Each of the themes was placed on “post-it” notes on the walls around the room. This process permitted preliminary exploration of the interrelationships among themes and provided a way to begin the process of grouping and ordering the presentation of the themes in a preliminary codebook. This procedure was followed until all the themes coded in the 10 transcripts had been aggregated into one pooled set of themes across all transcripts.

The use of multiple sites, multiple coders (the research team members) and the evolution of a common set of codes built from the ground up, helped triangulate the data, protected against bias, and assured rigor.

The research team subsequently worked from the preliminary codebook to conceptualize a final set of themes that could be subsumed under each of the original domains as well as new themes that expanded or extended across the original domains. The resulting revised codebook was used to develop a single set of findings across all of the transcripts. Each coder was responsible for reviewing this set of findings against his or her transcript(s), to ensure that all of the themes identified in individual coding had been incorporated. Each coder was also responsible for identifying and tracking any themes that did not seem to fit within the integrated set of themes contained in the codebook, which were retained as contrasts.

SMHAs were asked to conduct member checks. The purpose of the member check was to return to the original focus group participants to ensure that the themes made sense to them, and that they accurately reflect the discussion in the focus group. Each SMHA mailed out the preliminary report (summary coding) for their state to all their focus group participants. The mailing was accompanied by a cover letter from the research team that explained the member check process.

SMHA staff followed up this mailing with a telephone call. The research team developed a checklist for state staff to complete for each focus group participant. Basically, the staff member asked the following two things about each question set on the report: 1) “As you recall, do the themes reflect what was said?”; and 2) “Looking the report over, do the themes make sense to you?” If a participant responded “no” to either question (or both), then the staff member asked for an explanation and recorded this information (*Editor’s note: A complete set of member check materials is available in Appendix C*).

SMHA staff collected one additional piece of information during the member check. The member check provided an opportunity to find out which themes relating to mental health

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systems were regarded as most important to participants. To this end, during the member check phone call, each participant was asked to identify the three most important themes for each question set—the themes that he or she thinks should be given the greatest attention in seeking to strengthen or change the mental health system. Data on priority themes are not displayed in this report, but will help to focus the Phase Two work of developing relevant mental health system performance indicators.

The focus group participants were free to choose whether or not they wanted to participate in the member check phone call. If SMHAs had funds available, they were encouraged to pay a stipend to each person who chose to participate.

### *Trustworthiness of the Analysis*

The rigor and scientific integrity of qualitative research does not rely on traditional criteria of reliability and validity. Methods to assure the rigor of qualitative inquiry were adhered to in this study (Lincoln & Guba, 1985). “Credibility” or the accurate and unbiased presentation of the data (Lincoln & Guba, 1985) was assured through several procedures. First, typewritten transcripts were maintained and are available for checking. Second, as critical concepts were identified, and the coding scheme evolved, multiple research team members coded identical segments of data to ensure the coding scheme was credible. Member checking, or the confirmation of findings through follow-up discussion with respondents, was utilized. This process involved returning to interviewees to test interpretations, clarify any questions and seek alternative interpretations (Van Maanen, 1983). As described above, member checks were conducted by a state representative with consenting focus group participants by telephone to verify whether the abstractions of their statements (concepts) and their grouping into themes made sense to them, and whether they adequately captured the meaning of statements made in the focus group. These means ensured that the findings passed through several screens of verification, improving data reduction and reducing the potential for researcher bias. Finally, themes were justified through presentation of exemplary segments of verbatim text from the transcripts.

“Dependability,” or the ability to contend with emergent issues in the conduct of the research (Lincoln & Guba, 1985), was dealt with through the use of preparation and maintenance of a chronological methodological log of memos and successive codebooks that mark on-going refinement of the research methods and the evolution of the research concepts (Maxwell, 1996).

“Confirmability,” or the ability to relate findings and conclusions to the original data, was supported by preparation and maintenance of an audit trail (Lincoln & Guba, 1985). This includes maintenance of memos on the evolution of critical concepts, documents pertaining to research procedures and archived research materials. All themes were supported by data referenced in a manner that allows findings to be traced back to their original source in transcripts. Specifically, each excerpt includes a state code and line number so it can be traced directly back to the transcripts.

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“Transferability,” or the ability to relate the concepts in the study to established findings in the field of inquiry (Lincoln & Guba, 1985), was assisted by review of existing recovery literature. The literature review and discussion section relates this study to earlier studies, situating the findings of this study within the body of existing recovery knowledge.

Rigorous, constant, and comparative data analytic methods create a rich understanding of recovery processes. This study helps to build a set of interrelated concepts, and dynamic propositions or theories of processes concerning what helps or hinders recovery (Brewer & Hunter, 1989) that will be useful in future qualitative and quantitative research on recovery. The findings will be used to develop systems-level indicators of recovery in future phases of this project.



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## **Cross Site Findings**

There were 115 focus group participants. The ten focus groups ranged in size from 8 to 17, and averaged between 11 and 12 participants. Focus groups were scheduled for a five-hour period, with at least 30 minutes for lunch and frequent 10 minute breaks. Some focus groups finished early (30 minutes or so) and some went beyond the allotted time (up to an additional 45 minutes). All the focus group transcripts were formatted the same (e.g., double spaced) and ranged in length from 39 to 142 pages, averaging 103.

### **Description of Focus Group Participants**

One hundred and thirteen of the 115 focus group participants completed the optional background sheets. All the background sheets were entered into a database, with separate codes for entries there were left blank, not applicable or not interpretable. A series of runs were completed on this database to provide descriptive statistics of the study participants. The descriptive statistics on the demographic variables are reported first, followed by the mental health-related variables.

As indicated in Table 1, the majority of the participants were female (at least 58%). The mean age of participants was 47; the range in age was from 20 to 65. The majority of the participants were white (at least 69%); at least 12% were African-American/Black and 7% Native American/American Indian. Almost all participants identified English as the language they mostly spoke at home (at least 96%) with 1 participant reporting Spanish and 2 reporting both Spanish and English. The majority of the participants identified as heterosexual (at least 69%), 3 identified as gay, 3 as lesbian and 1 as bisexual. Comments provided by the 8 who identified as other noted that they considered themselves asexual or nonsexual.

Slightly more than half of the participants resided in urban areas (at least 51%), with the remainder fairly evenly distributed in rural or suburban areas. Six reported some high school education, 23 reported a high school or GED degree, and 40 reported some college or technical training. Close to half of the participants (at least 57 or 50%) reported completing college or a technical training program, with several completing graduate school (at least 14). Only 87 participants provided an estimate of their monthly income (included in the figure was their wages, salary and financial benefits), the median figure of which was \$1,000. At least 40 reported less than this amount (35%).

At least 30% of the participants had never married; at least 42% reported a divorce or separation. Two reported being a widow or widower and 2 reported living together with a significant other. At least 53% reported having children. Among those who reported living with family, 7 lived with their minor children, 4 lived with their parents, 2 lived with their adult children, and 1 lived with a sibling. Nine participants reported living with a roommate, 1 reported being homeless, and 2 reported living with pets.

**Table 1: Participant Demographic Characteristics**

		<b>Number</b>	<b>Percentage of 115</b>
<b>Sex</b>	Female	67	58%
	Male	44	38%
<b>Age</b>	20-39	13	11%
	40-49	53	46%
	50-59	36	23%
	60 plus	10	09%
<b>Race/Ethnicity</b>	White	79	69%
	African-American/Black	14	12%
	Native American/American Indian	8	07%
	Hispanic/Latino	5	04%
	Asian American	2	02%
<b>Primary Language</b>	English	110	96%
<b>Sexual Orientation</b>	Heterosexual	79	69%
	Gay/ Lesbian/ Bisexual	7	06%
	Other	8	07%
<b>Community</b>	Urban	59	51%
	Rural	27	23%
	Suburban	24	21%
<b>Education</b>	High School Degree/GED or Less	29	25%
	Some College/Tech	40	35%
	College/Tech Degree	34	30%
	Graduate Studies	23	20%
<b>Monthly Income</b>	0-\$499	9	8%
	\$500-\$999	31	27%
	\$1000-\$1999	32	28%
	\$2000 plus	15	13%
<b>Marital Status</b>	Married	20	17%
	Divorced/Separated	48	42%
	Never Married	34	30%
<b>Children</b>	Have Children	61	53%
<b>Living Situation</b>	Living Alone	52	45%
	Living w/ Spouse/Significant Other	22	19%
	Living w/ Family	14	12%
	Facility/Boarding/Supervised Living	7	06%

As indicated in Table 2, at least 84% of the participants reported having been diagnosed with a psychiatric disorder, and 70% of these participants agreed with the diagnosis. At least 25% of the participants reported also having been diagnosed with a drug or alcohol addiction. Eight-four participants reported being hospitalized for psychiatric reasons. Seventy-two reported the number of hospitalizations; the average being 10, the median being 6 and the range being 1 to 200. At least 75% of the participants reported being involved with a mental health consumer/survivor organization at some point.

Participants who reported receiving psychiatric diagnoses were asked to identify them. There were 165 entries as many of those listing diagnoses listed more than one. Diagnoses grouped in the other category included dysthymic disorder (3), panic disorder (3), suicidal (3), attention deficit/ hyperactivity disorder (2), personality disorder (2), seasonal affective disorder (2), agoraphobia (1), social phobia (1), multiple personality disorder (1), and conversion disorder (1).

**Table 2: Participant Mental Health Related Variables**

		<b>Number</b>	<b>Percentage of 115</b>
<b>Ever Received Psychiatric Diagnosis</b>	Yes	97	84%
	No	2	02%
<b>Agreed with this Diagnosis</b>	Yes	80	70%
	No	11	10%
<b>Ever Diagnosed with Drug or Alcohol Addiction</b>	Yes	29	25%
	No	74	64%
<b>Ever Hospitalized for Psychiatric Reasons</b>	Yes	84	73%
	No	19	17%
<b>Number of Times Hospitalized</b>	1-5	34	30%
	6-10	24	21%
	More than 10	14	12%
<b>Consumer/Survivor Organization Participation</b>	Yes	86	75%
	No	17	15%
<b>Self-Identified Psychiatric Diagnoses (multiple entries)</b>	Bipolar/Manic Depressive	42	37%
	Depression	41	36%
	Schizophrenia	15	13%
	Posttraumatic Stress Disorder	14	12%
	Schizoaffective Disorder	13	11%
	Anxiety	8	07%
	Borderline	7	06%
	Obsessive-Compulsive Disorder	6	05%
Other	19	17%	

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## Qualitative Findings

The research team, through a process of qualitative coding, codebook development, cross coding and recoding, developed a single set of findings across all of the transcripts. As previously stated, during the focus groups we asked questions about what helps and hinders with respect to particular domains (proxies for recovery). After coding each unique response, we then compiled the responses thematically first according to questions and second according to emergent themes. These themes include the domains we had asked the questions about and other emergent themes: basic material resources, self/whole person, hope/sense of meaning & purpose, choice, independence, social relationship, meaningful activities, peer support, formal services and formal service staff.

Before presenting the detailed findings, the following chart is presented to show the relationship between focus group responses to the questions and our thematic organization. The helping responses (Hp, the first column of each question set) involve implicit, positive interpretations. The hindering responses (Hd, the second column under each question set) often refer to a lack of what the theme is about or related hindrances that stand alone. Most themes were discussed across questions, or conversely, each question elicited responses that entailed most of the emergent themes. The very first question resulted in responses that can be grouped according to nearly all the themes. Thus unprompted, participants as a whole expressed a broad range of responses.

	Q Set 1		Q Set 2		Q Set 3		Q Set 4		Q Set 5	
	Hp	Hd	Hp	Hd	Hp	Hd	Hp	Hd	Hp	Hd
<b>Basic Material Resources</b>	*	*	*	*	*	*	*	*	*	*
<b>Self/Whole Person</b>	*	*	*	*	*	*	*	*	*	*
<b>Hope/Meaning &amp; Purpose</b>	*	*	*	*	*		*		*	*
<b>Choice</b>	*	*	*	*	*	*	*	*	*	*
<b>Independence</b>	*	*	*	*	*	*		*	*	
<b>Social Relationships</b>	*	*	*	*	*	*	*	*	*	*
<b>Meaningful Activities</b>	*	*	*	*	*	*	*	*	*	*
<b>Peer Support</b>	*	*	*	*	*		*	*	*	
<b>Formal Services</b>	*	*	*	*	*	*	*	*	*	*
<b>Formal Service Staff</b>	*	*	*	*	*	*	*		*	*

In the presentation of detailed findings, exemplary segments of focus group statements that were selected to illustrate each theme are included in the narrative. All transcript segments can be traced back to the transcripts; this information is displayed in the text of this report by state and transcript line numbers that appear at the end of each quote. Participating states included Arizona (AZ), Colorado (CO), New York (CNY) and (NY), Oklahoma (OK), Rhode Island (RI), South Carolina (SC), Texas (TX) and Utah (UT).

A summary chart of the findings is included at the beginning of each section. It must be acknowledged that the method we chose, that of focus groups, places emphasis on group findings. The data analysis used in this study, which segments findings into themes, and the use of summary charts to report these findings, may both reveal and conceal. For example, we did not set out to represent stories of individual recovery journeys per se and thus short narratives of such journeys are not fully reflected in our findings. The charts do aid in simplifying and summarizing the complex and rich data contained in more than 1,000 pages of transcripts. They also oversimplify. We stress caution in isolating these charts from the text and reemphasize that recovery is facilitated or impeded through the dynamic interplay of many forces that are complex, synergistic, and linked.

**Basic Material Resources**

<b>Hinders</b>
Poverty
Unsafe & Unaffordable Housing
Lack of Transportation
Barriers to Benefits & Entitlements
Lack of Communication Services

<b>Helps</b>
Livable Income
Safe & Affordable Housing
Transportation
Information & Advocacy on Services & Benefits/ Insurance Parity
Telephone Service
Resources from Social Networks

***Basic Material Resources: What Hinders?***

Mental health recovery is inhibited and more difficult to obtain when people have an inadequate income and live in poverty. Participants described the monthly SSD or SSI payments as insufficient for a family or an individual to live on, even before factoring in expenses for medication, services or transportation. A livable income obtained through a job and/or public subsidies was identified as a critical foundation for overcoming mental disorder. Beyond the income amount, participants expressed concern about lacking personal control of their own finances both for routine expenses and in terms of having discretionary money. Critical perspectives on “representative payee” relationships were expressed. As one participant from Colorado stated (1172) “You have to pay the payee \$360 a year and that’s money that I could use for shoes, clothing or a number of things.” Systematic deterrents and limitations to maintaining personal savings that are written into policy in benefit programs were mentioned as limiting the potential for recovery.

Participant consumers cited the exploitation of consumers for unpaid volunteer work as contributing to lack of income. Other contributing factors that harmed people’s ability to meet their basic needs included episodic mental or physical disability, and a high prevalence of persons with a history of trauma and abuse.

Unsafe, substandard and segregated housing and neighborhoods was articulated as a recovery concern for many participants as was the instability of frequent moves to new locations, “I

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am always confronted with the feeling of knowing that when I get connected, I am going to lose that connection because of my moving all the time” (NYC, 676). Another participant (CO, 108) said it sharply, “If you can’t have shelter, you can’t coordinate the rest of your life. If you don’t have an address for your SSI check to come to, you don’t have a place to set up for job interviews, you don’t really have any stability at all.”

A lack of the basic human need for privacy, whether from landlords, roommates or neighbors, was a prominent concern for all forms of housing. Participants, particularly those living in rural locations, said transportation problems contribute to isolation in their homes, difficulty obtaining services and participating in peer support activities. Others brought attention to the overlooked reality that limited access to basic communication via telephone, newsletters, computers, or written material reinforces isolation.

Benefits are a basic need for many people. The lack of knowledge of available resources and services or familiarity with eligibility requirements, legal rights or “how to navigate the system” was widely expressed by participants. “Like if you are not Medicaid-eligible you might as well go to Hell. You have to be absolutely destitute before you can get something” (NYC, 1188). Referring to the full complex of mental health and social services one participant summarized the viewpoint of many, “The system is a gatekeeper more than a caretaker. I swear sometimes the system doesn’t want you to know about some of the things that are available. Social services is set up to not give you the information, to not tell you what your entitlements are” (CNY, 122-128). Another participant offered an alternate viewpoint, “I think people just don’t even believe they have a right to a lot of things, even if they know about them” (CNY, 146). The effect of the continuous uncertainties of benefit levels was described by others, “when somebody is just doing really good, then they get to the point to where they are going to lose everything. They lose their meds and they’re right back down, and probably worse because they had hope and now they don’t have hope. It’s like the rug being pulled out from under them” (WA, 198-201). Or from a participant from Texas (140), “SSI/Medicaid is in control. I’m always worried every time they audit, every time they ask ‘Well we want to see if you are qualified.’ And then they’re going to change the rules on me.”

Widespread fears of the risk of losing medical and other benefits if one returns to work were expressed. Excess paperwork, constrictive rules and regulations, the absence of dental and other coverage gaps, the lack of parity in both public and private insurance for physical and mental health services, and the lack of salaried peer advocates were named as obstacles to access to benefits and services. Participants expressed that there were more resources available than they were able to locate and that each individual had to do far too much footwork to find information on services and what resources were available.

Low Medicaid reimbursement rates for service providers can limit those who will accept Medicaid payment for services, and long delays in available appointment times were also cited by participants as discouraging the use of services and hindering efforts to sustain their

individual recovery. Participants expressed that, “doctors and staff don’t know what it is like to be a consumer,” and proposed that all staff training include consumers as trainers.

***Basic Material Resources: What Helps?***

In challenging contrast to these recovery-inhibiting issues, many professed a resilient belief in the “American Dream” of equal opportunity and economic self-sufficiency in spite of the stark inequities in the distribution of resources. Participants expressed the need for a livable income through employment, entitlements, or volunteer subsidies. Participants said a range of housing options is needed. Several said safe, decent affordable housing, with and without supports is a crucial resource for recovery. “Because I have had a place where I could live and just be and feel safe, it really accelerated my recovery” (CO, 207). Transitional homes (for persons being discharged from hospitals, jail, prison, and others with unique needs, such as those who are dually diagnosed with addictive disorders) and specialized shelters were also mentioned.

Some participants described social, material and spiritual resources that were made available to them through networks of friends, peers, families and self-help groups and churches. There is a “need to take a more holistic view so that choices are available so far as not only treating our illness but our housing, our transportation, our training, our employment” (OK, 929-933). The need for frequently updated service or resource directories/contact persons was emphasized, and peer advocates and expansion of peer-run services were recommended as effective measures to improve access to available resources.

**Self/Whole Person**

<b>Hinders</b>
Negative Beliefs and Attitudes
Not Taking Personal Responsibility
Invalidation and a Lack of Information
A Lack of Discretionary Funds
Disabling Conditions/ Health Problems
Labeling

<b>Helps</b>
Positive Traits and Attitudes
Self Reliance/Personal Resourcefulness/ Dignity of Risk
Information & Education on Disorder
Self Advocacy and Self Determination
Self Care/ Self-Monitoring of Symptoms
Seeing Self as Whole, Complete Person

***Self/Whole Person: What Hinders?***

Participants talked about negative emotions such as shame, self-loathing and fear that interfered with recovery. For example, one participant said, “I had a lot of shame, even going to get help for me was like walking through a wheel of fire” (NYC, 191). Such negative emotions are often part of a self-stigmatizing process, whereby persons fear not being accepted, feel they get in their own way, don’t see themselves as worthy, distrust themselves

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and others, give themselves negative messages, maintain secrecy and see everything in their lives in terms of pathology. “What stands in the way is always me, I’m telling myself I’m not doing good” (NYC, 845). Feelings of self-protection can hinder making or maintaining connections with others.

Participants reported that hopelessness makes it difficult to engage in life. Often people accept stagnation and are pessimistic about the future. Such feelings can be compounded by self-absorption or a lack of motivation. Participants point out that these feelings or states of mind can interfere with the process of recovery. “I’ve always felt afraid of hope because someone’s going to steal it away or it’s just going to burst and go away. So I think it’s my own illness and my own thought processes that keep me from feeling hope and when I do feel it, I guard it extra carefully because I’m afraid it’s just going to go away” (RI, 1332-1336). Disorganized thinking was seen as another internal function that can get in the way of recovery.

Not taking personal responsibility is seen as hindrance to having control over one’s life. Being unwilling to take risks was mentioned as unhelpful. Others’ invalidation and criticism of one’s choices can hinder the process of self-care. A lack of respect for experiential knowledge contributes to this invalidation, which can make it difficult to believe in yourself and your self-care strategies. People talked about a lack of knowledge and information. In some instances people have had information withheld from them, which interferes with their ability to manage their disorder.

At times, a lack of money and funds hinders self-care because people may not have the discretionary funds to pay for activities or care that isn’t part of the formal service system, e.g., yoga classes, or for the services they want, e.g., medication. Often people are uninsured, or insurance or Medicaid does not pay for holistic health or new generation medications. Some participants expressed leanness of the mental health system absorbing all services under their umbrella, rather than people being able to access generic services within the community as part of their self-care/recovery strategies.

The disabling condition itself hinders taking care of oneself. Some people deal with multiple disabling conditions, which makes self-care all the more challenging. The nature of the psychiatric conditions, which can be cyclic and episodic, can also pose challenges. The strategies and activities one incorporates into one’s care do not always work or may be difficult to maintain given the nature of the disabling condition.

Labeling is viewed by many participants as preventing them from seeing themselves, or being seen by others, as a whole person with strengths and weaknesses. A participant from Colorado described it in the following way, “You’re bi-polar and you’ve got to be on medication. Heaven forbid, don’t think you are anything special, or you’re of value. You’re mentally ill” (CO, 2112). Labeling can hinder positive emotions. “What gets in the way with hope is labeling... I’m not one of the ‘mentally ill,’ not a client, I am a human being” (CNY,



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1546-1547). The labeling effect is large in the opinion of some participants, “It makes a huge difference whether you are viewed as a person or a diagnosis” (AZ, 2211).

### *Self/Whole Person: What Helps?*

Participants asserted that they need to view themselves as whole, as more than mental illness, as full complete human beings. Qualities and attitudes that helped participants in their recovery include: confidence, dignity, sense of humor, self-acceptance, self-esteem, hope, and trusting one’s self, including learning to trust one’s intuition. In addition, participants spoke of reclaiming their strengths and passions, being comfortable with self and being forgiving. The notion of having a positive outlook was related to hope. While self-acceptance had a connotation of resignation or acceptance of one’s fate for some, for others it signaled a more temporary feeling of adequacy, of “building from where I’m at” (NYC, 583).

Taking personal responsibility and making their own decisions was emphasized in various contexts as contributing to recovery. Self-reliance and personal resourcefulness were seen as helpful, especially when attempting to gain resources with which to live. Participants noted that motivation, perseverance, resourcefulness and self-sufficiency help in “making lemonade out of lemons.” Assuming a stance of personal responsibility for one’s life, one’s choices and one’s recovery and increasing self-determination and self-reliance were emphasized.

Participants attempted to manage their lives and mental health disorders in numerous ways. Self-management lessens the impact of the disorder. “Even if you do get worse, this can be compensated by the skills you learn to manage your illness... even if the illness does get worse, this does not mean that your life gets worse” (UT, 699). People find it can help to have order and stability in their daily living. Structuring one’s day can be accomplished in different ways including establishing a routine. Sometimes it helps to have someone assist in this process. Part of self-care is attending to one’s need for sleep. Other health conscious activities were mentioned like biking and yoga. Intellectual stimulation, through such activities as reading, was noted as important.

Taking care of oneself involves knowledge and information. Some of that knowledge is gained experientially, learned from the strengths one gains as a survivor. It may involve knowing that a painful or difficult time will pass, that one has come through it before, will survive, and has done so before. For some it includes actively avoiding unhealthy behaviors like the use of street drugs and involvement in unhealthy relationships. Other knowledge is gained by seeking information or education about the disorder and adding to the skills one has in understanding and potentially managing the disorder.

In addition to the process of self-care, many people turn to others, including peers, for support, and many seek out some manner of formal service. A woman from Washington described how she has learned to recognize “triggers” and went on to say, “But when it’s a new trigger and it throws you through a loop, you weren’t expecting it, you don’t know how

you're going to get through, and sometimes having people support you in that, reminding you that you can get through this too, it just helps so much having people believe in you, because you can have the foresight to believe in yourself, but you feel so shitty" (WA, 793-800). Participants emphasize the right and opportunities to take risks and fail as they struggle to care for themselves in a way that makes sense in light of their particular set of needs, strengths and vulnerabilities.

Participants asserted the value and necessity of advocating for themselves. "To be a self advocate, I think it is a very important part of a person's recovery if you want to use that word or awareness... their ability to help themselves" (RI, 1094). Self-advocacy can lead to positive gains in self-confidence and hope. "I find advocating for myself helps me gain hope" (CNY, 1296). Some participants emphasized that before helping others, "You have to advocate for yourself first" (NYC, 400).

### **Hope, Sense of Meaning, and Purpose**

<b>Hinders</b>	<b>Helps</b>
Dreams, Goals, Desires Demeaned	Developing a Sense of Meaning & Purpose/ Having Goals
Poor Quality Services/ Cutbacks	Meaningful Service Choices
Pessimistic Staff	Staff are Hopeful/ Realistic Optimism
Spirituality Discounted or Ignored	Spirituality Acknowledged
Stigma, Prejudice, Discrimination	Role Models, Friends & Peers
Sense of Hopelessness/ Negative Beliefs & Attitudes/ Self-Stigma	Positive Personal Attitudes/ Hope, Optimism
Disabling Condition Itself	Reclaiming & Appreciating Personal Strengthens/ Active Coping
Unfulfilled Basic Needs	Positive Personal Experiences/ Housing & Sense of Home/ Rejuvenation
Lack of Education on Recovery Resources	Gaining Knowledge and Becoming Educated

#### ***Hope, Sense of Meaning, and Purpose: What Hinders?***

Having a sense of hope, purpose and meaning in one's life supports recovery. A sense of hopelessness destroys meaning and purpose and the lack of meaning and purpose destroys hope. Some participants described processes that killed their hope, such as having their dreams, goals, or desires demeaned. One person stated, "You may have a goal in mind, and you may believe you can achieve the goal, and someone else will tell you... 'You're mentally ill, you can't do it'" (AZ, 2062). Being ignored or not being taken seriously by others diminishes the potential for recovery.

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The environment of mental health programs can hinder a sense of hope, meaning and purpose. Psychiatric hospitals were viewed by some participants as especially hope-diminishing environments, because people feel cut-off and then lose connections to their lives, relationships, sense of citizenship, while losing basic skills. Cutbacks in services and reduced access to community-based services are occurring in some managed care environments. “It seems everyday we lose. The waiting lists are getting bigger... It’s bleak” (TX, 1884). Poor quality services, and being on the wrong medication or over-medicated can make hope difficult to attain.

Hope and recovery is retarded through staff who do not know about the latest or most effective treatments, who hold low expectations and are pessimistic about the potential of their clients. There is a lack of challenge within mental health programs. On the other hand some providers foster unrealistic or false hopes that can also be harmful to recovery. The lack of opportunity to give to others in most programs also discourages hope, meaning and purpose.

People in the focus groups complained about the lack of focus on the spiritual dimension of recovery. Spirituality is of the greatest importance to some. The spiritual dimension of their experience, and the potential for developing meaning and purpose based upon spiritual or religious beliefs are frequently discounted or completely ignored by providers. “The doctor just gives drugs, he doesn’t do transpersonal psychology or spirituality. He is there to give drugs, and he did not care that the hospital experience destroyed me” (CO, 2086).

Attitudes associated with social stigma and active prejudice can make it difficult to develop and maintain a sense of meaning and purpose. The process of social stigma and labeling kills hope. “What got in my way was believing the label ‘chronic persistently mentally ill.’ That to me said I am never going to get better...” (SC, 909). Participants described being devalued and invalidated because of their psychiatric history. Being treated like a victim or a child hinders recovery. Some people found themselves being automatically viewed as untrustworthy or untruthful by mental health workers, family members or others because of their psychiatric history. Some said finding themselves and their ideas shot down/ or viewed as ‘grandiose delusions’ harms their recovery.

Negative attitudes on the part of others can block or destroy one’s own hope. Sometimes, other’s negative attitudes can be contagious. “If you get around people who are real downers, complainers, whiners and then it really sucks you in. I fall into their hopelessness” (OK, 2045).

A personal sense of hopelessness, pessimism and acceptance of stagnation hinders recovery. Lack of motivation is associated with the lack of meaning and purpose in life, and stands in the way of recovery. “Being alive is a lot different than living. Just being alive and maintaining. Maintaining to me means just that—no hope” (OK, 731). Self-stigma does great harm to meaning and purpose, and destroys hope. Fear of exposure as a person diagnosed

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with a mental illness, and of not being accepted, holds people back. Nondisclosure of one's challenge and secrecy can cut people off from meaning and purpose.

People said they often get in their own way. Some people do not accept personal responsibility for their recovery. They become highly self-absorbed and see everything in life in terms of their illness. People can feel unworthy; shame and self-loathing hinders hope. People give themselves negative messages. They can lose self-trust, and become unwilling to take risks, in part for self-protection.

Other internal conditions can injure a sense of hope, meaning and purpose. These include: other disabling conditions, poor health, fatigue, symptoms of mental illness and relapse, depression, including sensitivity to gloomy or overcast days, the continuing effects of trauma and the multiple losses one experiences as a result of experiencing severe psychiatric disorder. For some, the premature letting go of supports can challenge hope. Noncompliance with medications and dropping out of support groups can limit progress and lead to hopelessness according to some participants. In contrast, "Being told that you are on a medication, that you'll have to take it the rest of your life" (SC, 911) can also reduce hope.

Other external conditions such as unfulfilled basic needs, poverty, unemployment or employment in stagnant jobs interfere with hope, meaning and purpose. The lack of knowledge, especially the lack of illness education concerning diagnosis, the help one needs, the treatments and resources that are available, along with lowered educational opportunities, all lessen hope and hinder recovery.

### ***Hope, Sense of Meaning, and Purpose: What Helps?***

What helps people have hope and build a sense of purpose and meaning? The recovery process is supported through the assumption of a positive attitude or personal outlook, of learning to view "the cup as half full" or "making lemons out of lemonade." Some people talked about feeling more positive about their own challenges through comparing their situation to others who seem much "worse off"—examples include comparisons with other mental health consumers who are struggling more than they are, or functioning less well, people with life-threatening or terminal illness, and those with severe physical disabilities.

Achieving or maintaining a sense of personal dignity supports recovery. Awareness and appreciation of one's own strengths and talents is important. Participants described the experience of acknowledging and reclaiming or rediscovering personal strengths and passions, which had seemingly been lost in the experience of psychiatric disorder and its aftermath, or of regaining aspects of their personality that had been masked by the disorder. The ability to recognize and appreciate one's strengths as a survivor of psychiatric disorder, and sometimes, as a survivor of mistreatment within the mental health system, supports recovery. Here is how one focus group participant described this experience, "I'm valuing who I am at this age because of all the things I've survived, and I'm relishing my life better

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than I have ever done in my life” (UT, 490). A sense of humor can support having meaning in one's life when faced with psychiatric disabilities and stigma.

The process of "giving back" or contributing to others can be a source of meaning in life. It is meaningful to care for something, someone or a cause beyond oneself. “Part of what makes me feel like I have a purpose is that if I’m doing something positive for others...” (RI, 1135). Caring for other living things can include caring for animals and plants. Serving others is another very meaningful process that supports recovery. Making a difference in others’ lives gives meaning to one's own. Participants described ways that they contribute to others and to their local communities including participation in local projects, boards and committees unrelated to mental health concerns.

Having some sense of hope or optimism about the future and one’s potential for recovery were seen as important. People described hope in a variety of ways. “Hope is a positive refreshing energy that something good might happen” (CO, written comment). “Hope is the energy to do something different” (AZ, 2156). “Coming to that point where I am saying ‘Yeah. I can see a road, and there’s a future’” (TX, 732). In contrast, a few participants questioned whether hope was realistic, even necessary, and even mentioned that hope can be disabling. “Because it’s like if you just try a little harder, if you just do it a little differently, if you just keep plugging along, if you just keep doing this, or here’s a new treatment, or here’s a new parenting..., here’s something else you can do, and it always gives you that element of hope that is connected to this total fear of despair” (WA, 1560). Some felt hope needed to be made tangible or concrete to become real, in order to truly support recovery.

Other people, including role models, family, friends and peers can give one the hope one needs to move toward recovery. Others people’s attitudes can have an important impact on having a sense of meaning and purpose in one’s life. People need someone in their life who believes in them, who provides encouragement, validation, and positive feedback. Here is what one participant, who had lived on the streets for six years as a drug user, said about his turnaround to recovery. “I had lost all hope of having a meaningful life. So for me, making that choice to leave that life because someone opened my eyes and said, ‘[His name], what are you doing? There is hope in a different way of living.’... If ever I lose hope again my life will be over. So for me my lifeline is hope” (AZ, 1962). Positive expectations, opportunities, and challenges build hope, meaning and purpose, and engender recovery.

Having goals and choices supports recovery and makes life meaningful. Choices give life meaning. Services are more likely to become meaningful when you choose them. For some people, broad life choices such as choosing one's preferred quality of life, or how one wants to live are very meaningful. Participants talked about having dreams that spurred turnaround and recovery, and the rebuilding of personal goals as part of the process of rebuilding their lives. The process of active goal-setting focuses the process of recovery and gives a person a sense of what to strive for in the future. Some people shared that having or setting goals that are attainable or achievable helps their recovery process. Goals give one something to organize one’s life around, things to work toward, and means to measure how far one has

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come. There is a sense of satisfaction in achieving goals (sometimes goals other people had said you could never achieve). “I can set a goal and say I’m going to reach it, no matter what anybody says...” (RI, 962). Goals provide a long-term view in life, and a long-term view is important to recovery because it is often a long, slow process. Making recovery tangible through successfully taking many small steps increases hope. “If I gain an inch, I’m doing alright. I’m not hoping to gain a foot or a mile. I’m looking to gain that inch” (TX, 1852).

Taking personal responsibility for one’s situation and choices, and having control over one’s life help build meaning, purpose and hope. Moving toward independence and self-sufficiency, increasing motivation, and building confidence moves one forward in recovery. People bootstrapped their way into hopefulness through achieving small gains. In recovery, people rebuild their confidence, and come to trust in themselves and their intuition.

People said active coping or becoming active on their own behalf engenders hope, meaning and purpose. People get up and get moving, they take action based upon their personal resourcefulness, and through perseverance, over time, they make a positive life out of what had been seen as a bitter or negative experience. Having a positive structure to daily life can encourage hope.

Spirituality is a source of meaning that supports the recovery process. Spirituality allows people to endure psychiatric problems. “My faith kept me going.” (CO, 1811). “Most of my hope I’d call spirituality” (SC, 933). Some participants shared that their spirituality, faith, or connection to a higher power helps organize, guide or support their recovery. “Reliance on a higher power—the spiritual domain—expands my choices” (UT, 330) and looking toward my higher power “...seems to give me hope in every cell of my body. It builds me up” (UT, 598). Spiritual fellowship, church or spiritual community, and rituals or ceremonies of healing such as those conducted in Native American communities can promote a sense of hope, healing, community and connection to a source of hope, healing or power beyond oneself.

Gaining knowledge, and becoming educated can awaken meaning, purpose and hope. This involves learning about the disorder and new treatments. Learning extends beyond knowledge about one’s disorder and treatments, to the intrinsic value of learning and advancement of formal or informal education. Rejuvenation of meaning, purpose and hope can also come from positive personal experiences such as travel, time spent in nature and exposure to sunshine, having a good time, having decent housing and knowing one has a home.

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## Choice

<b>Hinders</b>
Limited or Lousy Options
Lack of Choices regarding Basic Needs (finances, transportation, housing, socially segregated settings)
Unemployment & Underemployment
Lack of Meaningful Involvement in Treatment Planning/ Lack of Right to Refuse Treatment
Limited Treatment Options
Forced Treatment & Coercion
Family & Professional Control
Lack of Skills in Choice Making
Disabling Condition Itself
Stigma/Discrimination/ Self-Stigma

<b>Helps</b>
Meaningful Options
Expansion of Choices regarding Basic Needs
More Job Choices
Educated on Treatment Options & Best Practices/ Self-Directed Planning/ Advanced Directives
Individualized Services & Treatment Planning/ Expanded Options/ Vouchers
The Freedom of Whether and How to Participate in Programs & Services
Self-Determination
Building Skills and Opportunities for Choice Making
Partner with Others in Recovery

### ***Choice: What Hinders?***

Choice is important to participants in many facets of their lives. Choice requires real options. Often the choices people are faced with are limited, the options lousy. Frequently, people are dealing with a lack of money and finances, and a lack of control over them. In terms of employment there is often a limited range of jobs, and most people said they were unemployed or underemployed relative to their skill level and capabilities. Housing options are often very limited and often located in segregated settings. “A lot of times we’re put in a situation where we’re told, ‘these are your choices, and we don’t necessarily recognize you have other choices.’ Living in residential programs can place many limitations on people... they said these are the people you can choose as your friends...” (AZ, 961). There are frequently transportation limitations, particular in rural areas. In general many people are confronted with a poor quality of life due to very constricted choices. Participants also cite their own lack of skills as compounding some of these problems.

Choices in recovery and treatment processes are hindered by coercion. Participants describe their recovery as being hindered by coerced consent forms, court mandated services and forced medication. Some participants voiced the opinion that even when people are homeless, forced treatment hinders persons’ ability to value or find meaning in services on their own and thus impedes their recovery. Controlling professionals and staff control are described as getting in the way of the exercise of choice and self-control. For example, a

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participant's refusal of one form of treatment is used by staff as an excuse to withhold participation in other treatments or programs. "And they're telling me if you don't take your medication, you're not seeing the doctor, and I just equate that with tough love and behavioral modification and it only puts a resentment in me and anger" (RI, 1550). More generally, "We've got your treatment program all designed. We don't want your input. Just keep your mouth shut. Sign this thing. This is what you're going to do" (OK, 256). Some participants said coercion in treatment and the lack of their meaningful involvement in treatment planning is reinforced by insurance practices. "Your financial and insurance resources should not depend on whether you are compliant with someone else's idea of a treatment plan" (SC, 439).

Psychiatric disorders can have an impact on one's mind, body, and spirit and can hinder recovery activities. Many participants describe their disorder as being disabling which can interfere with their capacity to make choices. A person's capabilities often vary over time due to the episodic nature of some psychiatric disorders. Other people may perceive you as a person who is consistently unable to make choices. Any expression of symptoms can mean you are treated as if you were incapable of making any choices, which hinders respect and efforts toward recovery.

Prejudice and discrimination based on psychiatric history interferes with exercising choice. Family control can make it difficult for a person coping with disorder to make her or his own decisions. The process of self-stigma or internalized stigma, which often involves deep feelings of worthlessness, can retard healing and recovery, limiting choices because options or progress are seen as unachievable.

### ***Choice: What Helps?***

Choices and principles of self-determination were seen as rights and the preferred method for engaging people and making services meaningful to them as individuals. People want the freedom of whether, and how, to participate in programs and services. Participants talked about the importance of having choice in staff, medications, and services. For example, "I'm not anti-drugs and I'm not pro-drugs. I feel like that should be a choice also. Whether or not you take heavy-duty medications" (WA, 361). Participants said we are, or should be, the choice makers, although choice is not always a reality in treatment.

The choices participants would like to have in their lives were not limited to the realm of treatment but included where they live/housing, finances, employment, personal living/daily routine, disclosure of disability, choosing how one sees one's self, one's disorder, one's situation, quality of life, who one wants to associate with, and self management. Participants expressed the desire for an expansion of choices (*Editor's note: The Codebook available in Appendix D of this report contains a more detailed listing*).

Choice is something that involves a learning curve in the opinion of some participants. People need opportunities for choice-making, they need to know that they have choice and



can make choices. Self-determination and self-responsibility are a matter of rights and expectations. People need to know something about what choices are available and when their choices are being limited. “It would be nice if a mental health center would say ‘These are the services that we should be able to provide to you. We can’t because of funding. But if we could, they might actually be more helpful to your recovery process than what we do have to offer.’ Because, there’s something that’s really empowering in having at least that knowledge” (OK, 856).

According to some participants, it can help to start small and progress in making choices; in this manner one builds skill in making choices. Time and patience should be respected as a person develops choice-making skills. It can help to have some support in making choices. With the exercise of choice comes the responsibility for making choices. Participants pointed out the importance of taking responsibility for choices. Again, taking responsibility for making choices needs to coincide with the opportunity to make choices in the recovery process. A person from Central New York described their involvement in making important choices this way, “The last time I was in the hospital I chose to go, developed my own plan, what groups I wanted to participate in, why I was there and developed my own discharge plan” (CNY, 1734). People can remain at the helm and gain practice in making decisions about their life and management of their disorder. This may include the right to take risks, make a mistake, and to fail. Failing can be part of the process according to participants.

At the same time that people want the freedom to choose “to be who I am” they also express the opinion that they would like to share, collaborate and partner with others in their recovery process. They want ultimate control of their own lives, but recognize a role for others who are willing to share in the decision-making, not take over, or take control away from them. To have choice one must also have choices or real options—things to choose from. Participants noted that options are necessary, and must include alternative paths that are accepted as legitimate choices, or at least paths that are not blocked. The enactment of an individual purchase of service voucher system was suggested as a way to make consumer choice and individualized services a reality.

### Independence

<b>Hinders</b>
Paternalistic Orientation of the System/ Lack of Respect for Experiential Knowledge
Involuntary & Long-Term Hospitalization
Negative Attitudes & Beliefs (Fear, Lack of Confidence)
Risk & Fear of Losing Benefits/ Clinical Supports/ Safety Net

<b>Helps</b>
Making Own Choices and Decisions/ Increased Consumer Voice in System
Self-Determination/ Advanced Directives
Interdependence & Partnership
Having Affordable Housing, Car, Job, etc.

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<b>Hinders</b>
Stereotyping, Prejudice, Discrimination, Labeling

<b>Helps</b>
Basic Human and Civil Rights & Freedoms

***Independence: What Hinders?***

Independence was expressed as both a process and goal of recovery. Numerous external and internal factors were described as hindering independence. Participants talked about how formal services such as long-term hospitalization and the lack of alternatives to involuntary treatment hinder recovery (*Editor’s note: Further details on these processes are contained in the section on formal services*). The service system’s paternalistic orientation hinders independence. This can be compounded by one’s own attitudes and the disabling condition itself. As a person from the New York City group said, “I depend so much on the mental health system that I have no confidence, no value in myself” (NYC, 236). Sometimes family enhances dependency, particularly when they are uneducated about the problem. A participant who emphasized the combination of his own emotions, and other people’s negative reactions getting in the way of independence said, “Fear keeps people from gaining that independence. Why should you bother trying if, say, you’re going to have another major episode of depression, and you are going to be thrown back out with the garbage? Why should you even bother trying again?” (TX, 1211).

The risk/fear of losing benefits and the loss of clinical supports/safety net is a related concern. For example, “Fear of losing medical benefits was a major obstacle to acting independently in seeking employment” (CNY, 972). Conservators and representative payees were seen as getting in the way of independence. Being dependent on medication, particularly having to take medications, “for the rest of my life,” (NYC, 880) was mentioned by some participants.

The lack of respect for experiential knowledge was discussed as a hindrance to recovery. There is a lack of respect for the hard-earned knowledge a person with mental illness has gained through experience. Some group members pointed out that they may lack knowledge about positive mental health and physical health concerns that can hinder their efforts towards recovery. More broadly, many viewed the public’s lack of knowledge about mental disorder, and how ignorance can lead to stereotyping and prejudice, as a hindrance. As one man explained, “What gets in the way of my independence is when someone looks at me and sees ‘schizophrenia,’ their negative perception, and that’s what gets in my way of gaining independence when they don’t look at me as an ordinary person” (RI, 855).

***Independence: What Helps?***

Participants emphasized the importance of making their own decisions and choices. Independence in this sense is closely related to self-determination. People spoke of the importance of freedom including such basic freedoms as the freedom of speech. “My road to

independence would have to start with freedom of speech, including the right to say ‘I feel suicidal’” (CNY, 722). Some participants related independence to having basic material resources, such as income, housing or transportation. For example, “Affordable housing is independence to me” (CNY, 139); and, “Basically my independence is based on the fact that I currently have a car” (RI, 901).

Participants related the need for increased or continued consumer voice in the mental health system when talking about achieving their independence collectively. Participants also saw a role for consumers as having an influence in the overall governance and policies of peer- and professionally-run programs and research, such as this national project. They viewed themselves as having the right to decide about their individual status and treatment. For example, “An advance directive is a good thing for me; it gives you some power over what happens to you, you have someone you trust during a time of crisis” (CNY, 872).

Several participants felt independence was less important than embracing interdependence with peers, family and with others in the mental health system who are open to partnership (*Editor’s note: See further exploration of these issues in the Sections entitled Formal Service System Staff*). In the words of one group member who said she needs to accept that interdependence is the way that she needs to live, “so that means that I really have to listen to the people in my life, listen to feedback about what I’m sounding like and acting like, at a level that I would have found completely unpalatable when I was planning my life as an adult” (RI, 797). Achieving balance between being independent and interdependence requires reliance on oneself, and support from others. “As long as I don’t mix my private meds with street meds because I’m dually diagnosed, I’m fine. But if I go off the deep end, luckily I have people who do help me to stay tethered” (RI, 885).

### Social Relationships

<b>Hinders</b>	<b>Helps</b>
Inadequate Social Network/ Social Isolation	Extended Networks/ Kinship Ties/ Friendships/ Affinity Groups (faith communities, tribes)
Emotional Withdrawal/ Personal Isolation	Personal Ties (at least one person)/Intimate Relationships
Lack of Information for Families and Friends	Openness to New Information, Strategies, Healing/Advocates within Social Networks
Controlling Family Members	Supportive & Accepting Kin
Lack of Social Skills	Communication/ Social Contact (e.g. fun)/ Balancing Solitude and Social Togetherness
Stigma, Prejudice, Labeling, Negative Media Portrayals	Volunteerism

<b>Hinders</b>
Disabling Conditions/ Health Problems
Social Status/ Immigrant Status
Trauma Experiences
Substance Abuse

<b>Helps</b>
Access to Means of Communication (i.e., phone service, Internet)
Social Choices
Mutual Aid/Interdependence

***Social Relationships: What Hinders?***

Participants described an inadequate network of friends, family, peers, other sources of social contact and mutual aid as a cause of isolation that hinders recovery. “You’ve got to meet people first somehow, but there’s a big wall, like bamboo curtain or the Iron Curtain—and we’ve got the illness on this side, it’s pretty hard to get on the other side” (TX, 1652). Individual emotional withdrawal was described as reinforcing the absence of a social network. “I have to force myself to get connected. It’s like an emotional pry-bar to make me do things. I try to get involved with doing something positive for others, not just something for me” (RI, 1132).

A lack of practical information and education on mental illness and wellness for families and friends is widespread, and the resulting lack of understanding was cited as compounding distrust and inhibiting both individual recovery and the capacity for potential support. Family member who are controlling extend dependency at the expense of interdependence and equality in decision-making authority.

A lack of opportunity and locations for learning and practicing social skills was described by some participants as contributing to isolation, both within the general community and from consumer/survivor peers. Inadequate funding of peer-run services and clubhouses was cited as contributing to this problem. Negative, stigmatizing and prejudicial public attitudes toward people who act out of the ordinary, or who carry the label, history and/or actuality of a mental disorder, serve to inhibit social connectedness. “I felt like I had this big sign on my forehead that said ‘mental case.’ I didn’t want to be around people or communicate with them” (CO, 272). Participants expressed strong opinions that, with few exceptions, media coverage of “the mentally ill” reinforces fear of association among the general population because of the highly distorted images of potential danger and likelihood of violent behavior by persons coping with mental health problems. Ironically, given the frequently stated negative perceptions of the media, some said, “it is just easier to sit and watch TV than to take the first scary step and talk to somebody” (SC, 593).

Physical health, disabling physical conditions, and episodic mental disorder itself were reported by some participants as limiting their ability to form or maintain social relationships. Personal histories of abuse or severe trauma were disclosed and discussed by some as powerful deterrents to forming or maintaining trusting ties, especially intimate ties, with others. “Past incidents of trauma get in the way of getting and staying connected with

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anyone,” one participant stated, “I would rather have animals” (CNY, 1254). Addiction to drugs or alcohol, and dependency on the segregated social world of obtaining and using addictive substances emerged as a major issue for some. For most people in recovery the substance abuse subculture is a world that they willfully attempt to avoid. Undocumented immigrants have culturally diverse understandings of mental illness, and language barriers, combined with the immigrants’ uncertain legal status, results in fears of utilization of services or benefits. They often live in segregated neighborhoods and have low wages. These factors, taken together, reinforce isolation.

### ***Social Relationships: What Helps?***

The certainty of being able to count on at least one person who knows and believes in you as a whole human being, not reducible to a diagnosis or any current state of disorder, provides a foundation for some participants feeling that they were not alone in this world. Beyond that one person, family members were often identified as social mainstays. Friends, immediate family, extended family and tribal affiliations—people who believed in them even when they could not believe in themselves, who accepted the illness and believed they could recover—were named as the primary sources of positive social support. “My advocate wife sees to it nobody gives me a raw deal. I don’t know where I’d be today if it hadn’t been for my wife” (UT, 642). Interdependence within natural communities—quite literally as a tribal connection by one Native American, and loving ties of kin of all ages—were the foundation for recovering independence. In this sense, interdependence or mutual aid enabled the re-establishment of solid ground and centering necessary for increased independence.

Participants who were employed or served regularly as volunteers frequently identified co-workers as friends outside of the workplace as supporting connection and recovery. The ability to have light-hearted social contact, to socialize simply for the fun of it, was emphasized among participants who stressed that fun is not reserved for people who seemingly do not have mental health problems. Intimate relationships including marriage were identified by some as enduring anchors or beacons of light in their recovery journeys. One participant said both marriage and divorce were helpful.

The exercise of choice concerning whom one wants to associate with, and the process of letting go of people who pull you down were important for some focus group participants. For example, a former substance abuser with a mental health diagnosis expressed the desire and need to not return to the old neighborhood and an environment where street drugs were readily available.

Some people shared the importance their faith life, spirituality, church membership, and ritual or ceremonies in their faith communities as supporting relationship and recovery. In one participant’s life, tribal affiliations made a difference. “When someone in our family gets sick we see them as a family, my sisters move right in, we are the spiritual healers, this is the Native American way” (CNY, 1749). “I found a new church home where people understood

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my illness and accepted me as a person with an illness and were able to support me” (CO, 183).

For some people, mental health self-help groups and formal or informal peer groups of consumer/survivors were their community of choice. Others also actively sought relationships with persons in the general community, based on similarities of likes and dislikes, having no correspondence to mental health problems, past or present. For example, “Having places and opportunities to connect with outside of mental health centers helps you get connected or bond with people on something other than your symptoms” (WA, 1002). More generally, “Human contact, whether it is in conflict or in agreement, it is still contact with people and it gets you out of the house and a reason to feel good about yourself” (TX, 1591). Participants saw regularity of contact as important. Some use outreach agreements to counterbalance isolation and the tendency to self-isolate. People learned to balance time for the satisfaction of togetherness with the need for solitude or “downtime” as a part of their recovery.

Openness to learning new information, healing strategies, or ways of cooperating with others was identified as the key to positive communication, including within families. Shared understanding is a prerequisite for family members or mental health care proxies to be effectively involved in advance planning for a crisis. Some people described the difficulty they had learning how to talk about their own needs and learning how to set healthy boundaries with others.

Beyond small group or one-to-one communication, other forms of communication were discussed, including: the crucial need for telephone, and the importance of other ways of communicating such as e-mail, Internet, newsletters and newspapers, conferences, trainings and membership organizations. Some pointed out “community” is lacking in “community mental health services.” Many sought to become rooted and find or build their own networks of mutual aid and support. The ongoing work on forming and improving social relationships was seen as an important aspect of mental health and mental health recovery.

### **Meaningful Activities**

<b>Hinders</b>
Unemployment/ Role Loss/ Under-Employment/ Limited Range of Jobs
Employment Disincentives in Benefits
Not Respecting Personal Decisions About Job Readiness or Interest
Lack of Training & Education Opportunities
Exploitation of Volunteer Work

<b>Helps</b>
Choice among Meaningful Employment Opportunities
Program and Policy Decision-Making
Respect Choices/Readiness for Work
Educational Advancement (e.g., formal, self-directed)
Volunteer Work

<b>Hinders</b>
Prejudice, Stigma and Discrimination/ Disclosure Fears

<b>Helps</b>
Understanding & Respective Employers/ Accommodations
Advocacy Group Participation/ Systems Level Advocacy/ Community Organizing

***Meaningful Activities: What Hinders?***

Participants recounted situations in which the disabling conditions of mental illness led to unemployment; with this loss of work role came a loss of identity. This loss was compounded by the extreme pessimism about the return to work expressed by mental health staff from the onset of the illness. “The first time I ended up in the hospital with a breakdown, the first thing that they tell you is ‘You’re never going to work again. You’re never going to be able to handle the stress’” (TX, 775).

Participants reported that not being able to work was very debilitating. “When I lost my profession, there was just a big void there. There was very little support. There was no place to go to, to find a new way to fit in, to find a new way of life” (CO, 185). This lack of support in addressing unemployment (as well as in helping to maintain employment) was a common experience. “I’ve worked since I was 14 until I was 40-years-old, and it’s horrible for me not to be able to work, and they are not giving me any kind of support to help me get back on my feet” (TX, 870). Government benefits that are needed during periods of unemployment, however, often contained disincentives and “Catch 22’s” with regard to regaining employment. Participants pointed out that the fear and risk of losing benefits often stops them from seeking employment.

Unemployment is very common, regardless of how strong the desire and how persistent the effort is to get work. When seeking employment, participants are confronted with a very limited range of jobs. When they do get a job, they find themselves underemployed in stagnant jobs. Advanced education and training is seen as a way of improving one’s employment chances, but participants report a lack of access to such opportunities. On the other hand, some participants felt pressured to engage in employment activities when they were not ready. Sometimes engaging in one’s own process of recovery is the work that the person needs to focus on. “I worked for 15 years and spent 10 in the military—I’ve worked all my life, and I feel I have earned that right to take this time to let myself heal” (CO, 267).

People drew a clear connection between their unsuccessful efforts to engage in meaningful activities and the prejudice, stigma and discrimination associated with having a mental illness. Local communities, employers, and organizations, seem enmeshed in negative and stereotypical views of mental illness, often promulgated by media messages that fuel misunderstanding. Participants described their fear of encountering stigma and discrimination and the anticipated accompanying rejection. Negative anticipation of stigma and

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discrimination prevents some people from seeking out opportunities to engage in meaningful activities.

Even when one is successfully employed, fear persists concerning how employers and co-workers will react if they learn about one's mental illness. "I just took a job right before December and I'm worried every day if I have a bout of depression. They say you don't have to tell them that you have a mental illness, but if they find out, they'll fire me and say, 'Well, you lied to us. You didn't tell us you were sick.' You know that fear is with me all the time" (TX, 967). Job discrimination proved particularly painful when it occurred in settings that were supposedly more enlightened, such as mental health organizations.

Participants noted that volunteer opportunities within the mental health system could come with a cost—the result of feeling devalued and financially exploited. Participants said they are repeatedly encouraged to volunteer to help their peers (and programs become over-reliant on volunteer labor), but the underlying message is that their efforts are of such limited value that they do not merit pay. "The state agency which is supposed to help people with occupational rehab services, told me that because of mental illness, I cannot go to work in the mental health field—which is what I want to do—because I shouldn't be counseling people, or I shouldn't be around other people because my illness would prevent me from helping someone else. And I'm like, duh, I have a better understanding than anybody else, I think, and I've been working in this field on a volunteer basis as a peer advocate, a mental health advocate. I just want to find a paid position for it" (RI, 963). At a minimum, psychiatric labeling comes with the cost of being viewed or treated as someone of questionable value.

### *Meaningful Activities: What Helps?*

Several participants stated that gaining and having meaningful paid employment greatly contributes to recovery. "The self-respect that comes with doing meaningful work will increase the positive things in your life, even change some of the negative things" (SC, 410). Another person said, "I think employment is the way to go, the best therapy there is" (CO, 157).

Access to, and choice among meaningful work opportunities, and a focus on career development are fundamental to recovery. Participants want their decisions respected in reference to when they are ready to go back to work and where they want to work. People want worthwhile opportunities to develop and strengthen their job skills and abilities. Participants view equal employment opportunities as beneficial in their employment efforts. Employers who demonstrate respect and understanding, who are open to considering (and providing choices in) accommodations, are seen as extremely valuable in achieving meaningful employment.

Another avenue of meaningful activity is that of engaging in knowledge development and educational opportunities. Participants report an intrinsic value in learning. Taking a class, reading, self-directed education, community involvement through arts, and leisure activities



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provide intellectual stimulation, enhancement and enrichment to one's life. Advancing one's formal education through completing a GED, technical training, and/or college is not only meaningful, but it also contributes to one's employment potential. As stated by one participant, "We need more education so that you have a wider choice of what type of employment you can get" (WA, 366). For such opportunities to occur, however, participants noted that there must be access to, and an expansion of choices regarding general and advanced education programs.

Some participants viewed volunteer work as very meaningful. As one person said, "Volunteering is as valid as work" (CO, 249). Through volunteer work, participants report a sense of service, i.e., contributing to and helping others, or making a difference. "The rewards that come from doing things as a service to others, there is a kick back that comes with that, that keeps my faith and my image of myself up" (UT, 614). People cited this sense of service, of doing something positive for others, as their reason for getting involved in group- or system-level advocacy work as well.

Engaging in advocacy was seen as a means to gaining voice, of moving towards independence. Participants identified personal or self-advocacy (*Editor's note: detailed in the Self/Whole Person section*) as integral to recovery, but also identified the importance of engaging in joint or systemic advocacy activities. Participants describe their advocacy involvement as tending to start by connecting with peers (attending meetings and sharing experiences) and then seeing others undertake advocacy. Being a part of situations in which others engaged in advocacy can trigger one's own sense of power. Sharing what it is like to experience ignorance, injustice, stigma, and inequalities, and validating that these were common or shared occurrences, helped provide people with the strength to speak up. Channeling anger concerning injustice gave people the energy to seek change. As one participant put it: "The only way to get people to notice it, or to understand about the mental illness, is fighting the system. Showing people, 'Hey, I'm human. You can't just throw me away'" (TX, 1861).

Participants expressed a desire for expanded advocacy efforts, more choices in advocacy activities and respect for their efforts (for example, having a stronger voice in legislation). Participants describe how advocacy gives them something to do when other opportunities, such as employment, are taken away or restricted and/or employment is too difficult to sustain due to the disorder itself, or when they feel dependent, and possibly trapped, on government benefits. Some people said when a person doesn't have anything to lose, when he or she doesn't get services from the mental health system, it is easier to undertake advocacy. People who are not direct consumers of agency services are more able to work on changing mental health programs that are not working well.

Participants also described being involved in advocacy and community organizing activities beyond the mental health system, such as working in efforts and movements to address poverty. People talked about the importance of engaging in community involvement through

advocacy on public issues, such as being involved in local schools and serving on community committees.

Participants also noted that it wasn't necessary to be an advocate to be invited to the table. They valued experiences of being invited to, and involved in, program and policy decision-making forums, such as serving on advisory committees. They talked about how opportunities to participate in forums and focus groups can be as meaningful as a good job. Paraphrasing a Texas participant, such opportunities help people recognize that what they have experienced and seen has value, that their opinions have value, and that they have value.

### Peer Support

<b>Hinders</b>	<b>Helps</b>
Lack of Funding/ Infighting over Limited Funds	Adequate Funding for Peer Support
Peer Support Not Available in Many Regions, especially Rural	Wide Availability of Peer Support Resources
Limited Participation (e.g., same few people participate)	Diverse Models of Peer Support (e.g., support groups, warm lines, case managers, etc.)
Limited Leadership Development Opportunities	Role Models & Mentors
Formal Service Provider and Staff Control/ Not Controlled by Members	Exposure to Self-Help/ Self-Help Philosophy
Lack of Independent Peer Support Resources	Support Resources run by Consumers
Professional Mistrust of Peer Support	Consumers employed within Traditional/Formal MH Services
Lack of Transportation	Accessing Other Self-Help Supports & Services (e.g., AA, NA)
	Sharing Common Experiences

#### *Peer Support: What Hinders?*

A lack of federal, state and local funding for peer-run and peer support services were identified as deterrents to recovery. Peer support, educational, and advocacy opportunities are not available to many urban, suburban and most keenly rural areas. "Going to the different groups has helped a lot and at the same time it has hindered me in that the infighting within groups, because of fighting for the same money, has split the joint efforts" (CNY, 1224). As stated by a participant from Oklahoma (OK, 2807), "I have heard people say 'I am getting more out of this support group than from my doctor, my talk therapist, or anywhere else.' Now then, if we're that important, why is there no funding for trained facilitators and starting new support groups?"

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Some participants commented on limited attendance at peer group meetings, for example, “You get the same people, it doesn’t get any bigger” (TX, 1717); or “Peer groups can develop a core group of people who do all of the advocacy stuff and never step down and nobody else gets a chance to step up. Knowing when to step down helps increase relationships and get connected” (SC, 668). The distinction between services that were truly governed by members being served, versus either formal agency control or staff control of decision-making, was discussed.

The lack of peer support resources that are independent of, or an adjunct to, formal mental health services hinders the expansion of self-help and peer-run efforts in general. In addition, many professionals and mental health providers will not refer clients to self-help groups, 12-step or otherwise, unless the group is professionally run. This has been a major source of tension, while a sense of partnership should be achievable. Transportation is a major problem in maintaining involvement in peer services, especially for those living in rural and suburban areas. People find it difficult to access evening or weekend activities and statewide or national conferences and training.

### ***Peer Support: What Helps?***

Peer support services utilize the principles, philosophy and many of the methods of self-help groups—such as, “helping people is helping yourself, really” (NYC, 649), and “support from others is very important, especially from others who are in the same predicament you are. They know what you go through. They have been through it and have survived” (TX, 1258)—but are distinctive in that they employ former consumer/survivors as staff, managers or board members. Many participants said something about role models and mentors. “I have seen these people who have been where I have been and are overcoming those obstacles. It gives me hope that I can keep my aspirations for my life too” (AZ, 1974); “If you can do this so can I” (UT, 387); and from Texas, “To promote recovery you need resources like alternative services, like drop-in centers, clubhouses, places where people can congregate together to share ideas and share experiences and help each other gain confidence so they can eventually deal better with their mental illness and return back to the community” (TX, 183). The advantages of peer staffing can also carry into inpatient services. “The people that helped me the most in the hospital admitted that, yes, they were mental health consumers. They were hired, and when they were hired no one knew” (OK, 2850). Peer advocacy for those least able to advocate for themselves was viewed as important. “It should be a requirement that mental health peer advocates and outreach advocates are available in every county or region” (CNY, 426).

The network of AA, NA, Double Trouble and other nationally affiliated and independent self-help groups parallel peer services, with much crossover in vision and activities. Participants mentioned a key part played by a role model for success (in Alcoholics Anonymous terms, a “sponsor”) or mentor. “People further along in their recovery, mentoring people that are not as far along” (TX, 1332). People said that consumer-operated services or peer-run services, including drop-in centers, peer case management, peer

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professionals, warm lines, social clubs, and other consumer social activities such as dances or parties spur recovery. Not all of these operations or roles are conducted in a way that segregates consumers from other persons receiving or giving help.

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## Formal Services

<b>Hinders – Org. Culture &amp; Structure</b>
Culture and Organization that is Pathology-Focused/Illness-Focused/ Dominance of Medical Model
Lack of Change & Innovation
Lack of Holistic Orientation (e.g., neglect spirituality, physical health)
Access Limited to Those in Crisis
System Promotes Dependency/ Paternalism & Maternalism
Stigma within the System
Social Segregation
Funding Problems
Lack of Consumer Voice on Personal and System levels

<b>Helps - Org. Culture &amp; Structure</b>
A Recovery-Oriented System with a Vision of Recovery/ Extending Support beyond Traditional Boundaries/ Consumer-Driven
Encourage Innovation/ De-fund or Transform Ineffective Practice & Programs
Holistic Approach/ Proactive Approach supporting Preventative Measures/Positive Mental Health
Multiple Strategies
Self-Responsibility/ Fostering Growth & Interdependence/ Assistance with Letting Go of Dependency on System
Fully Committed to Consumer Voice/ Support Risk Taking/ Freedom to Fail
More Tolerance for Diversity & Unusual Behavior
Adequate Funding and Equitable Distribution of Resources/ Monies Reinvested in Community/ Voucher System
Consumers Employed Within System at All Levels/ Consumers Involved in Decision-Making Processes Such as Staff Hiring & Firing/ Mandated Consumer Positions on Boards & Committees/ Office of Consumer Affairs/ Ombudsman Program

<b>Hinders – Programs &amp; Services</b>
Coercion & Forced Treatment
Treatment/Medication used as a means of Social Control
Debilitating Effects & Experiences of Long-Term Hospitalization

<b>Helps - Programs &amp; Services</b>
Forced Treatment Avoided
Freedom of Whether & How to Participate in Services & Meds/ Self-Management of Medications
Inpatient Services as Last Resort but Available/ Small Scale/ Alternatives to Hospitalization/ Self-Directed Inpatient Care/ Advanced Directives Respected

<b>Hinders – Programs &amp; Services</b>
Substandard Services/ Poor Quality Assurance
Limited Access to Services & Supports/ Timeliness, Time limits
Fragmentation of Services, Eligibility Restrictions
Lack of Individualization
Lack of Needed Range of Services, Treatments and Options
Lack of Education for Consumers, Family Members and Community (e.g., illness, self-care, services, etc.)
Inadequate Continuity of Care

<b>Helps - Programs &amp; Services</b>
Quality Clinical Care/ Consumer-Doctor Partnership/ Up-to-date Treatment Knowledge/ Clean & Modern Program Environments
No Waits/ Flexible
Coordinated Services Across Problems, Settings, & Systems/ Effective Case Managers with Low Caseloads & High Pay/ Disengagement or Reductions in Services Based on Consumer's Self-Defined Needs
Tailored to Individual/ Wide Range of Choices as to Who Provides, What is Provided & Where Provided
Peer Support Services/ Therapy & Counseling/ Atypical Meds/ Family Services/ Employment Support & Career Development/ Respite Care/ Integrated Dual Diagnosis Services/ Jail Diversion and Community Reintegration Services/ Etc.
Patient Education/ Illness Education/ Information on Meds, Effective Treatments & Services & How to Secure, Rights/ Family Education/ Public Awareness Education (anti-stigma & pro-recovery)
System Navigators/ Extensive Outreach & Support (multiple languages, 24-7, minority-focused)/ Homeless Outreach/ Safety Net Services
Access to Records/ Can Change Inaccurate Information
Early Intervention & Public Screenings/ Outreach to Churches, Schools, Communities

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### ***Formal Services: What Hinders?***

The culture and orientation of the formal mental system can hinder the potential for recovery. Systems currently lack an orientation that emphasizes development of positive mental health, a positive balance of living and lifestyle, or a holistic perspective. There is a lack of needed change and innovation that would move systems toward a recovery-orientation. Formal systems ignore important aspects of life that support recovery. For example, they generally avoid spirituality and the spiritual dimensions of psychosis although this area is very important to some consumers. Mental health services can actually be toxic or re-traumatizing. Some people described the adverse effects of mental health treatment, such as abuse in mental hospitals, that hindered their recovery.

The dominance of the medical model can have a negative impact on recovery. The illness-orientation of the system overly medicalizes and pathologizes people's life experiences. In medical model systems, every experience, need, and concern comes to be viewed as a symptom of a mental illness. Peoples' lives are not only about symptoms. Some participants said under the dominant medical model there is an over-dependence on medication as the primary approach or single tool. Many systems concentrate services on medication and medication management, but this alone is an ineffective strategy to assist people in achieving recovery. People described over-medication, being treated with the wrong medication, or ineffective medications as impairing their potential for recovery. Medication side effects can increase stigma and limit the possibility of recovery.

A crisis-oriented formal system also hinders recovery. When the system is crisis-oriented, versus rehabilitation- or recovery-oriented, the person's condition has to deteriorate and reach the level of crisis or emergency before they can receive help. "You have to be sick in order to receive the benefits to stay well" (SC, 530). Crisis-oriented systems do not support recovery and well-being, they only respond to deterioration. As one participant from Texas said, "We have a system that's based on helping on an emergency basis only. Does it have to take an emergency before somebody gets help? Does it have to be when somebody pulls the trigger or slices their wrist before somebody finds the help that they need?" (TX, 1275). Many systems have poor crisis and emergency services; some rely on poorly trained and poorly run emergency services in general hospitals.

The orientation of the formal system promotes dependency among consumers, which is the antithesis of recovery. Many systems are infantilizing and dependency-engendering. The formal system does not support the development of self-responsibility. According to participants, formal services are often paternalistic/ maternalistic, e.g. day treatment is like "adult babysitting," which harms the potential for recovery. "I got out of the system because it was doing nothing but dragging me down and keeping me down" (OK, 2832). Learned helplessness may result when a system encourages dependency. "We lose that ability to have the courage to take a step, in a direction where it is just a little bit risky and the system is all too willing to say... 'It's OK we'll take care of you'" (AZ, 1521). Social entitlements can both reward and retard dependency. If people complain about aspects of the system, there can

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be retaliation for advocacy or filing a grievance. Discrimination and stigma within the system also impedes recovery.

Forced treatment hinders recovery. Many systems still rely on coercion/force, with the emphasis on system control of individuals rather than self-responsibility. People provided examples of many forms of force, including coerced consent forms, court-mandated services, forced medication, mandated connections, state regulations that demand a doctor's report to the department of motor vehicles saying it's okay for you to have a driver's license, and being forced to accept treatment in order to receive homelessness assistance. Formal systems that have a social control orientation hinder recovery. Such systems are characterized by controlling professionals, staff control, and power inequities. Coercive systems limit and remove choices, and can use treatment, services, and medication as means of social control. For example, "They use meds as a way to control your behavior—it's like a pharmaceutical handcuff, a medication straightjacket" (SC, 1332). There is a lack of alternatives to involuntary treatment and overuse of seclusion and restraint and shock therapy.

Some focus group participants viewed hospitalization as hindering recovery. Hospitalization/institutionalization, especially long-term hospitalization, has a negative impact on recovery. Participants reported that such settings cause them to lose living skills, and re-traumatize them. The lack of access to the outside world gives the sense of being locked away—"out of sight out of mind." When they developed relationships with other consumers, the hospital discouraged continuing contact with them. Some felt as though they were in detention/sentenced to the hospital and that their experiences were criminalized. People lose the sense of being a citizen and community member. Physical and emotional abuse and the abuse of power and authority in hospitals are detrimental. In some cases the history of abuse in hospitals lead people to fear such settings. The use of seclusion and restraints can impair recovery and leave lasting effects. There is a lack of alternatives to hospitalization.

Systems that hinder recovery are stigmatizing. The attitudes, culture, policies and traditions of such systems operate from the perspective that the client is inferior to staff. In addition, the illness perspective may be promoted at the expense of seeing consumers as whole unique individuals. "When I was being eyed as being mentally ill and crazy, every single move I made was suspect. Even the things that were normal in my life were suspect... I think that limits our control over our lives and finding out who we are, and what our rhythms are, finding our own song, which may be different..." (CO, 786). The system is often focused upon system self-preservation rather than being consumer focused/consumer driven. "When you've got directors providing programs that are patronizing and stigmatizing—if the idea didn't come from them, it's not valid—that is the worst kind of stigma" (OK, 2766). People are often socially segregated in mental health programs and stay inside an insular world.

Several systemic structural characteristics of formal system were viewed as hindering recovery. Systemic funding problems include lack of funding for effective programs, especially highly effective peer-driven services. Systems are often not open to consumer providers; consumers are not in the loop to know about or compete for requests for proposals.



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Funding cuts jeopardize assistance, and financing can support the needs of the system rather than the needs of the consumer. For example, “You’ve got terrific insurance so automatically you need to be in [the hospital] for 30 days and they’re gonna give you 30 days of treatment. They find out that your insurance doesn’t cover mental health like it’s supposed to. You’re gonna be fine with three days of outpatient” (OK, 2435).

Some people feel they are viewed as a source of billing or as a commodity that generates revenues, rather than as unique individuals with unique needs and personal freedoms. “I remember going by a drop-in center and I planned to leave for lunch with someone else, but was told ‘you can’t leave because we couldn’t count you for billing’” (NYC, 373). Funding mechanisms can reward providers for keeping people in a dependency mode and continued service utilization, rather than rewarding them for assisting people to achieve recovery.

Incomplete oversight and accountability allows poor services. There is poor oversight of programs and systems in some areas, and a critical lack of quality control of services. Some participants described substandard service/poor quality of care in the formal system. “Everybody is getting the same treatments that they got five years ago that weren’t working then and we’re expecting different results. It’s not any good unless we’re willing to try something new, innovative, different” (OK, 1921). Substandard services can be offered at the expense of other desired services. “Don’t have the funds to do that [support groups] and yet we watched as private for-profit organizations came into our state and charged \$125 a day for day treatment programs. So \$125 they’re collecting, to let those people sit there and drink coffee and smoke cigarettes” (OK, 2813).

Poor quality psychiatric services can result in inappropriate (mis)diagnoses and treatment, as well as short sessions that do not constitute quality care. People are not supported in attempts to adjust or change meds, and their help-seeking is often rejected. “It’s basically just an ushering in and an ushering out—‘Here’s some meds, we’ll see you in 32 days’” (CO, 2633).

Access to services is difficult; there are many barriers blocking access to formal services. Some believe there is no meaningful access to services for any but the very wealthy or very poor. There are inconsistencies among programs, as well as fragmentation and discontinuity in eligibility and income guidelines. People are frustrated at having to go to too many places to receive services. “Having to navigate that system almost made me stop going because it was just impossible” (OK, 221).

People encounter too many hurdles, or have to jump through too many hoops; there are too many different rules and obstacles to having one's needs met. There are many eligibility restrictions or limited eligibility to needed services. For example, “I went through a bad time when the medication stopped working and then they just added all these medications and I kind of short-circuited. I wish I had the support of being able to get some little extra support of getting over that bad time. I wouldn't have had to leave that job” (TX, 739). There is too much paper work, and too many forms to fill out to receive needed services or entitlements. Many systems lack specialized services for trauma survivors and people with dual diagnoses.

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There is fragmentation of substance abuse and mental health services and a lack of places for people who are dually diagnosed to receive quality treatment.

The system can serve as a gatekeeper rather than a caretaker. For example, “I was already a nurse and they treated me like ‘you’re a nurse, just get yourself together. You should know better. What are you doing here?’ type thing” (WA, 1816). There is a lack of timely access to services and care. In some mental health systems and entitlement programs, people are routinely denied services or benefits when seeking help; appeals are necessary to gain benefits or services. Long delays, several steps before accessing services, denial of services to walk-ins, and long waiting lists serve to hinder recovery. In some areas there is no movement off of waiting lists, which effectively blocks people from receiving services. The lack of service coordination, poor case management, and high caseloads also make access to services difficult.

There is often a lack of choice and selection in services; the system decides for you what you want or need. There is a lack of access to services that are based on self-defined need. A lack of individualized services, and the absence of individual service plans hinder recovery. Systems lack the needed range of program/ treatment options, e.g. psychotherapy, case management, psychosocial rehab. There is lack of funding for supportive employment and lack of emphasis on higher-level employment (*Editor’s note: The Codebook, available in Appendix D of this report, provides additional detail on service gaps*). Transportation gaps and barriers also make access to services and supports difficult. Programs lack self-help orientation, and there is a lack of referral to self-help options; often programs don’t promote peer support.

The general lack of education and information regarding formal system services is detrimental to recovery. People lacked illness education/patient education, including information on diagnosis, practical education on self-care and how to improve. “I felt very sort of blind-sided and mystified by the whole process, and I trusted the doctor and I didn’t know a lot about the medications I was given. I was in a vegetative state for a long time and a lot of it, I think was due to the sedating effect of the medication...” (RI, 375). There is inadequate information on the help, resources and treatment options available. Systems withhold information in such areas as available program options/resources, right to refuse treatment, new medications. There are few options for gaining good information. People lack knowledge of, and/or a belief in, having rights. Families lack needed education and support. Systems don’t know how to engage, support and respect families. The broader community lacks awareness and information about psychiatric disorder and recovery.

Records and treatment plans are often not shared with consumers, and some records contain faulty information. The lack of confidentiality also hinders recovery.

People described important issues concerning continuity of care and continuity of caregiver that retard the potential for positive recovery. Several focus group participants indicated such problems are occurring or worsening with the rise of managed care. There has been a loss of

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clinical supports/safety net in some systems. For example, people lose important services as their mental health improves. When resources are tied to certain levels of care, levels of functioning, program guidelines, or the funding of certain programs, services that promote or support recovery can be denied. For example, “I’ve finally taken hold of myself, I’ve taken WRAP training [Mary Ellen Copeland’s Wellness Recovery Action Plan], I’m coming out on my own, I’m taking charge of my own life and they say, ‘Fine. Go get that job.’ At that point, I am totally and completely castrated from the mental health society. No supports. No visible supports whatever. Three months into that job, two months into that job, it’s a little bit more than what I expected at the moment, and I just need one visit back with my CMHC to help me maintain that job, but I can’t have it.” (OK, 880).

Services can be terminated without the person's consent. People are terminated without their agreement because they are doing too well. Some services are time-limited which doesn't match well with on-going or intermittent need for supports. Insurance benefits or behavioral health guidelines can drive what is offered, rather than being responsive to the individual's needs. Indigent people and working people without Medicaid lack access to expensive psychiatric medications.

Follow-up and continuity of caregiver is often lacking. “I’ve got another consumer who died from lack of somebody following up, making sure she was all right. Her air-condition broke, called up the center. [The Center] called her up and said ‘get in touch with your landlord,’ which is, you know, normal... Five days later she was found on the floor with a 107 degrees temperature with brain damage right off the bat. Four months later she did not recover” (TX, 2202). There are many more changes of treatment providers under managed care, with the result that you never know who you will see, no one knows who you are, and you have to provide your whole psychiatric and life histories over and over again to each new provider. Sometimes a new provider steps in and prescribes treatment without consultation, “I had a Dr. introduce himself and say you need ECT. I’d never seen him before in my life” (SC, 1299). There is a loss of continuity of services under managed care, and over-regulation that creates barriers, but does not contribute to quality of care. Procedures and programmatic limitations in HMO's can hinder recovery. Formal services have an inflexibility, or rigidity, that doesn't match well with changing or dynamic individualized needs. System- and program-level innovation is undermined by rigid guidelines and a funding stream attached to outmoded guidelines for requests for proposals.

The lack of meaningful consumer voice in formal systems lessens the potential for recovery. Many formal systems lack an organized peer advocacy system for individuals in the system. While consumers are more often involved at the program and systems level in the formal system, there is often tokenism in the use of consumer leaders. Consumers are seldom involved in planning services. Consumers who participate in systems-building activities are frequently not paid for their work, nor are they kept informed of the results of their efforts.

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### ***Formal Services: What Helps?***

The culture and orientation of the formal system should support recovery. All programs should be recovery-oriented. “The system should assume that every person that walks through the door has the potential for recovery—rather than the opposite. Just assume that recovery is possible” (SC, 1286). Because recovery is larger than the formal system, the system will have to extend support beyond its traditional boundaries.

Formal processes should be used to promote and foster a recovery-oriented system. For example a state-level body such as a mental health advisory council should develop and adopt a vision of recovery.

A recovery-oriented system would encourage people to grow and would foster interdependence. Formal services should “let people know they are capable of growing, that they don’t have to live in the holding pattern” (AZ, 2730).

A recovery-oriented system would have a holistic approach. It would see people as whole persons and unique individuals. Such a system would use many strategies, rather than relying only upon medication management, or a strict bio-psychiatric or medical model orientation as the single approach.

A recovery-oriented system would be more proactive, less reactive. Such a system would support preventative measures. Services would not be only for “worse off” problems and people would not have to wait to access services until they are experiencing a psychiatric crisis.

Certain structural characteristics of the formal system would support recovery. A recovery-oriented system would be adequately funded. Resource distribution would be more equitable, and funding would not be targeted only toward the most severely disabled or people in crisis. Monies would be reinvested in the community. Such a system would encourage innovation and would stop funding or transform ineffective practices/programs.

A recovery-oriented system would be consumer-driven. “The system needs to know that they work for us...” (CNY, 279). Funding would support consumer choice. A voucher system could be created. Consumers would have vouchers to purchase the services and supports he or she believes are needed. A recovery-oriented system would employ consumers at all levels. More consumers should be employed as workers and in State Mental Health Agencies. Some participants expressed a numerical approach to ensure consumer-driven services, e.g. 51% of mental health department staff should consist of consumers. Another idea is to make all positions in any provider agency, like case manager or counselor, 75% consumer-staffed positions. All levels of personnel from hospital care worker to policy maker would include those with direct experience of psychiatric disorders.

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Forced treatment including forced outpatient treatment would be avoided.

A recovery-oriented mental health system would be fully committed to consumer voice and participation. Participants gave examples such as involving consumers much more in decision-making processes, and inviting consumers to the table, so they can say what it is they value while giving input in forums and focus groups. Consumers would be able to demonstrate to decision makers what they are talking about. Consumers should be involved in decisions to hire and fire staff. Every system would have an active Office of Consumer Affairs or ombudsman program. There would be mandated consumer positions on the community service and mental health boards, committees and subcommittees. A recovery-oriented system would be accountable to consumer-oriented results and outcomes.

A recovery-oriented mental health system would be flexible rather than rigid, tailored to the consumer, and would give consumers a wide range of choice in services and supports. Services and supports would not be cut-off based on standardized criteria, but rather would be reduced in conjunction with a person's self-defined needs. "The program should be flexible to meet your needs. It's not how you [the consumer] can benefit us [the provider] by sitting in this program, but how can this program benefit you?" (SC, 597). Individualized services and "catered care" should be available based upon the consumer's ideas of what will help him or her achieve recovery.

Choice in services should include who provides the services, what services are offered, where the services are provided, and the kind of approach taken. People would have choices between public and private mental health services. People should be able to control the type of therapy and treatment they receive. Choices are particularly important in the areas of a) the freedom of whether and how to participate in programs and services, and b) in the use of psychiatric medications. The system should "help and support you in what you want to do, not telling you what you can do and what you are not capable of doing" (TX, 797). Service wraps should be provided for new and innovative programs.

A recovery-oriented formal system would provide consumers with more choices and a wider range of options. "One of the choices is to be able to stop the therapy or program or drug that is clearly not working and try something else" (SC, 333). There should be more tolerance for diversity and unusual behavior. The system should also support people in taking risks rather than avoiding risks and allow people the freedom to take on things and fail. "Not be afraid to let someone fail a little bit—as long as you provide some back-up support for them, some safety net behind them" (TX, 799).

Peer services should be available, including warm lines (i.e., non-crisis supportive call lines) and support groups. Peers would connect with people in hospitals, jails and while homeless to help them with transitions and point the way to recovery. Support groups would be available, including in rural areas.

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Quality clinical services would be available that would include access to psychotherapy and counseling. There would be more frequent and longer doctor visits, review of medications, and consumers and providers would work *together* to find the right medication, or the right combination of medications. Systems would offer access to existing atypical medications, and to newly released medications. Some of the newer medications can make a great deal of difference in the potential for being active in one's recovery. "I am on the first drug that let me get out of bed... and I haven't seen a side-effect yet. And that was a long time coming," (CO, 1615) said one participant, and, "Just because of a new generation of medication, I can be in the hospital one week and functioning this way today," said another (OK, 2272).

Physicians and psychiatrists would have up-to-date knowledge about medications. Medication, when done right, can help consumers feel empowered. Self-management of medications can aid recovery. "Finally I found a doctor... I said 'I'm so tired of taking this. It keeps me sleepy, it gives me, you know...' and he seen the light. He said, 'You are aware of when you're depressed. You're very much aware of when you are going into a manic phase. Here's the medicine. Now you take it when you know you're going into a mania or when you realize you are manic. And you take the other when you get depressed and I don't mean you have to take them every day.' And I am well aware of when I need to take them and I do take 'em when I need to" (OK, 1222).

People would be assisted to succeed in the world of work. Vocational services and supports would be available; people would have opportunities to learn job skills; people would have access to supported employment. There would be support for higher-level employment, and professional status employment rather than steering people exclusively into low-level jobs. "A real job coach supports you in trying to find a good job" (TX, 866).

There should be crisis outreach and support, as well as respite care recovery-oriented day programs, psychosocial programs and consumer-run clubhouses. Program environments should be clean and modern.

In spite of the need for a wide range of services and supports, some participants stressed that people should be assisted to let go of dependency on the system, and use the formal system only when needed.

People should be able to access inpatient services, particularly as a last resort. Some people need to use the hospital or a "safe" setting, for example, to escape from/deal with pressure. There should be small units with personalized services. Supporting and facilitating self-directed inpatient care helps recovery. Alternatives to hospitalization should be available. There would be respectful implementation of advanced directives.

Systems should have patient education and illness education so people can have opportunities to learn about medications/ psychiatric disorders. They should have improved information resources on medications, current advancements, and medication side effects. People need better information on existing resources, the most effective services, and how to get them;

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their rights; and procedures regarding treatment and services. A recovery-oriented system would help people know their options, including all available resources, and it would have updated resource listings. People would have access to all the information in their medical records, and the ability to challenge and change inaccurate information.

Family education supports recovery. Family and consumers should have support/ education, including joint family/consumer groups.

There is also a need for public awareness education. Increased attention should be paid to educate the public to reduce stigma and understand recovery (anti-stigma campaigns). “Have dramatic-type education that actually uses people that are suffering and shows how they can recover and how they can be functional” (TX, 1235). Early intervention, public screenings, and involvement of churches, schools, families and the general health community is needed to identify people in need of services and hook them into care so they can avoid prolonged disorder.

A recovery-oriented system would provide people with help in navigating the system. Access would be facilitated through extensive outreach efforts; 24-hours-per-day/7-days-per-week telephone access to services in all spoken languages; and evening services. Outreach to minorities was recommended. People would have regular and frequent contact with the system.

Active case management can facilitate recovery. Case managers should have low caseloads, and more case managers should be hired. Case management would be reformed and good case management offered. The system itself should be more coordinated, and the system should take care of its employees and pay them adequately.

Systems should coordinate across settings and across multiple problems that people face. Transitional services should be available. The system should include homeless outreach, specialized shelters, and safety net services (decent affordable housing, access to education, basic needs/supplies). Dual diagnoses programs and integrated dual diagnosis services should be available and people should have access to Double Trouble, Narcotics Anonymous, and Alcoholics Anonymous. Jail diversion alternatives, jail-based services, and services associated with release from prison would promote recovery.

### **Formal Service System Staff**

<b>Hinders</b>
Discontinuity/ Burnout/ Overworked
Low Expectations/Negative Messages
Misunderstanding/Mistrust

<b>Helps</b>
Continuity/ One-on-one Relationship/ Availability
Hopeful/ Positive Expectations/ Belief that Recovery is Possible
Understanding, Trustworthy/ Honest/ Open

<b>Hinders</b>
Coercion/ Power-Over/ Formal Roles
Paternalism/ No Understanding of Consumer's Experiences/ Superior/ Disrespectful
Culturally Insensitive/ Devaluing/ Not Much Staff Diversity
Foster Dependency/ Discourage & Undermine Consumer Participation
Inadequate Knowledge & Training (on trauma services, recovery process, effective meds & treatments, etc.)

<b>Helps</b>
Continuity/ One-on-one Relationship/ Availability
Listened to/ Believed/ Staff are Authentic, Respectful, Supportive, Caring, Responsive, Have Humility
Culturally Sensitive/
Fosters Self-Empowerment
Improved & On-going Training & Education/ Consumers Involved as Trainers

***Formal Service System Staff: What Hinders?***

The power differential typical in the relationship between staff and consumers often inhibits recovery. The power differential is evident in, for example, the lack of meaningful consumer participation in treatment planning and staff abuses of power. People said staff don't seem to know what it is like being a consumer, and this does not help recovery. "Each [staff person] should spend a week in the state hospital. Then be told 'surprise, surprise, you have to stay one more week'" (CO, 2052). Staff often relate to consumers paternalistically. Paternalism may be expressed in various ways including how staff communicate with consumers. For example, "I'm not dumb... This group leader would go 'Now you know that's really, really good! We're all proud of you'...in a voice like Mr. Rogers" (CO, 1911). Participants talked about staff controlling by pressure, threats and force. Such actions undermine a person's ability to relate as a responsible person. Thus, coercion is seen as hindering recovery.

Participants have experienced mental health program staff as disrespectful e.g., expressing condescension and not listening, infantilizing, lacking in trust, culturally insensitive, uncaring, untrustworthy, and devaluing. "I was treated like I was a nobody. Nobody really cares about you. Keep your damn mouth shut because you're not important. You're just something that we're here getting paid to take care of. We don't want any trouble out of you." (OK, 246). "The trust issue is a big issue in the system. I've been lied to so much" (TX, 1907). "The attitude, culture, policies and tradition that the client is inferior to staff must be changed" (NYC, 1014). These attitudes hinder people's sense of self and ability to relate and interfere with consumer participation in treatment. For example, "I don't want to cry all the time, and I want to be able to get out of bed, but I don't want to be 950 pounds either. I didn't have this side effect before I took it. Give me the right to tell you what's happening with my body and the medication is not working, or else the side-effect is much worse than not taking the medication" (OK, 634). Low expectations on the part of staff, particularly when they do not believe in recovery, create an atmosphere that is unsupportive of recovery.



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Staff burnout or staff being overworked has a detrimental effect on the lives of the people they come in contact with. Participants cited these conditions as something that hinders their recovery. Role issues were discussed. Staff are seen by some as often staying in their formal role, e.g., acting detached, objectifying people, which is in stark contrast to the qualities participants find supportive of recovery. Too often staff are inclined to reward dependency. In reference to the problem of being overworked, staff can be burdened with paperwork that removes them from other roles more conducive to supporting recovery.

Participants expressed the opinion that inadequate knowledge and training among staff is a hindrance. Lack of up-to-date treatment information, e.g., about medications, and lack of professional training in the area of trauma services inhibits the recovery process when formal services are sought or received. Finally, some participants noted that staff are not culturally diverse enough, including that there are not enough African-American/Black staff.

### ***Formal Service System Staff: What Helps?***

A staff-consumer/survivor relationship built on partnering and collaboration is viewed as the type of relationship that supports recovery.

The most important thing is a sense of partnership... I remember the first time (and it was very recently... within the last year), that a psychiatrist actually sat down and talked to me, actually listened to what I had to say. I was feeling a lot of fear and apprehension about some important tasks I had in front of me. He said, 'We're going to get through this together, you know, this is a team effort.' News to me. Twenty years of living with [this disorder] no one ever told me that before... This concept that we were in partnership—both of us doing whatever we could to enhance my recovery, understanding that the primary responsibility is with me for my own recovery, not stepping back from that at all—was such a novel thing (AZ, 2373).

In such a relationship, consumers are listened to, believed, asked for their opinion, and treated equally. As one participant said, "The right staff with patience, time and understanding can help you move along toward recovery" (NYC, 239). Participants find staff attitudes and qualities when they are authentic (e.g., trustworthy, honest, open), respectful, supportive, caring, culturally sensitive (e.g., to gays) and based in humility, as promoting recovery. "In all my years experience with psychiatric professionals, the one thing that's been most heartening is when the professional acknowledges the common humanity, theirs and mine, ours together" (CO, 2172).

Positive expectations on the part of staff, particularly their belief that recovery is possible, are supportive of the recovery process. "Because if you don't have a service provider that believes that you can recover, all bets are off. You might as well just go home and watch Jerry Springer. Because they are not going to support your choices. They're going to say, oh, you don't want to go back to work. Your symptoms might come back. Oh, you know, school,

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hummm, I just don't know if you can do that" (WA, 628). "There have been in my life a few really good providers who actually said, 'Of course you can get better, and we'll figure out a way to do that.' You have to have a provider who also thinks that recovery is possible." (SC, 1006). Being told by professional people and non-professional people that "you don't have to be more than you can be, just be what you are, and be what you can be, and don't try to worry about reaching super-high goals if you don't want to" (WA, 1469) has also been experienced as helpful.

When staff are responsive in their roles, participants find this helpful to their recovery. Particularly helpful is the one-on-one relationship and when a staff member fosters self-empowerment. Some participants cited practical support, often in the form of a person who will play multiple roles, as a key support provided by formal service staff.

The recovery process is facilitated by staff availability and having ready access to staff. Being able to reach someone was appreciated and seen as beneficial; being able to go in to see a provider, even if unannounced, was desired (although possibly an unrealizable ideal). Continuity of staff or caregiver was noted as helpful. Some people had long term relationships with professionals or paraprofessionals and these were viewed as important to recovery.

Participants expressed the opinion that training and education of staff should be improved, including better training of ER staff. Participants recommended that consumers be included as trainers. Participants pointed out that doctors needed better education on medications and med interactions, which would assist those seeking the "right combination" of medication.

### **Member Check Results**

All nine SMHAs conducted member checks with their focus group participants regarding the coding report for their respective focus group. Fifty-nine (51%) of the original focus group members agreed to participate. States averaged between 6 and 7 member check participants, with a mode of 5 and a range of 4 to 12. Thirty-nine of the participants were female (66%). Participant ages ranged from 29 to 64, with an average age of 49 and standard deviation of 8.

Member check participants read the report of themes identified in the transcript for their focus group (the initial coding framework). Each participant was asked if the themes reflected what had been said for each question set. There were 413 possible responses (59 participants multiplied by 7 question sets). Thirty-two entries were missing, 14 of those regarding Question Set #7. A "confirmability index" was calculated on the remaining 381 responses to determine the proportion of respondents who agreed that the coding captured the original content. In 379 responses, participants agreed that the themes reflected what had been said, which represents an agreement rate of 99.47%.

For each focus group question set, the participants were also asked if the themes made sense to them. Forty entries were missing, 15 of those regarding Question Set #7. The "credibility

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index” was calculated on the remaining 373 responses. In 360 responses, participants were in agreement that the themes made sense, an agreement rate of 96.5%.

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## **Discussion and Implications**

The goal of this Phase One Report is to add to the developing knowledge base on mental health recovery, in particular, to expand our understanding of what helps and what hinders recovery in the ecological context of the individual within his or her social environment. This section of the report discusses the research findings, describes the limitations, explores the research and policy implications, and identifies next steps in the research project.

### **Discussion**

While recovery is a deeply personal journey, there are many commonalities in people's experiences and opinions, as the more than 1,000 pages of focus group transcripts analyzed from around the country attest. The findings we present are comprehensive. We did not censor the data, nor pick and choose which ideas to present. We had to work hard to reduce the data to a manageable set of themes, and some of the richness, nuance and personal stories unfortunately are lost in data reduction processes. While there were many clear, shared themes across and within groups, part of the paradoxical nature of recovery is that people also have very divergent experiences and opinions. What helps one person at one time and place to move forward on his or her recovery journey is not important to another person, or can even hold someone back.

Having acknowledged this shortcoming, our research findings add important information to the recovery knowledge base. For the first time we have systematically elicited insight and knowledge on mental health recovery from a diverse and broad base of consumer/survivors across the nation. The Austin Workgroup, after a review of the recovery measurement literature, and the five-person research team, each with significant recovery research experience, chose to focus the inquiry on five domains that play critical roles in recovery. The selected domains were resources/basic needs, choices/self-determination, independence/sovereignty, interdependence/connectiveness, and hope. By focusing on a relatively narrow scope, we hoped to capture a greater depth of knowledge. The importance of these domains was borne out in the study. Analysis of the data expanded and revised this set of domains to include the critical roles of basic material resources, the self/the whole person, hope/sense of meaning/purpose, choice, independence, social relationships, meaningful activities, peer support, formal services, and formal service staff.

### **Findings in Relation to the Existing Knowledge Base**

It is important to place the findings of grounded theory within the context of the existing body of knowledge. This segment of the discussion section relates study findings to other research concerning what promotes recovery, as well as to a smaller body of findings concerning barriers to recovery. By comparing the current study findings with existing theory and research (a process called triangulating the data) we can have confidence in the findings

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of the study and build a stronger, empirically-sound knowledge base concerning underlying patterns and processes that support or impede recovery.

The broad finding that recovery is a personal process that extends well beyond the boundaries of traditional mental health systems has been supported in other work (Tooth, Kalyanansundaram, & Glover, 1997). Leading investigators in the field have suggested that processes within the mental health system can either promote recovery and encourage resilience or they can serve to retard active coping, and induct people into “careers of chronicity” (Harding, Zubin, & Strauss, 1987). Qualitative research on personal stories or narratives on recovery confirm that recovery processes are complex and multifaceted, irreducible to a simple construct (Ridgway, 2001).

Blanch, Fisher, Tucker, Walsh, and Chassman (1993) examined the content of consumer-practitioner forums. They found recovery was an ongoing process that required overcoming the assaults of stigma, discrimination and abuse as well as the development of a renewed sense of free will and self-control. They found that recovery was facilitated by undertaking self-directed coping strategies, participation in valued activities and important human relationships, feelings of hope, and a sense of personal meaning. All of the findings of Blanch and colleagues are also found in the current study.

Sullivan (1994) used a semi-structured qualitative protocol to interview 46 individuals who met his specific criteria for recovery (staying out of the hospital and involvement in meaningful activity, despite severe and persistent psychiatric disorders). Similar to the current research, which indicates recovery relies strongly on social factors and positive relationships, Sullivan found recovery was facilitated by self-help and mutual assistance, relationships with significant others, and having strong relationships with caring and supportive helpers. His interviewees said self-will, knowledge and acceptance of their disorder, self-monitoring of symptoms, stress management, medications, vocational activity, and schooling were crucial in their recovery. Our findings, while similar to Sullivan’s, suggest that some people have made progress in their recovery by not buying into “the standard line” about the disorder as they cope with ways in which problems manifest in their own or other’s eyes. In addition, in our findings, medications—when prescribed in a way that maximizes benefits and minimizes side or adverse effects—are seen as a part of an array of services that should be available (but not forced). One of Sullivan’s unanticipated findings was that most of the people he interviewed viewed spirituality as a positive force supporting their recovery. The significance and importance of spirituality was also found in the focus groups conducted in the present study.

Australians Tooth, et al. (1997) used structured and semi-structured interviews to gain consumer perspectives on their recovery from schizophrenia. A total of 57 people provided a wealth of information in areas such as life adjustments they made due to the disorder, turning points and the personal recovery process. They also examined barriers to recovery and processes that supported their recovery. Participants identified determination to get better, acceptance and self-management of their disorder, and taking control of their lives and not

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letting their lives be dominated by their illness, which parallel findings in the current study. Participants were focusing on their strengths, and found it a barrier to have helpers focus on their deficits, which stripped them of hope—a concern they shared with our focus group participants. They too found that helping relationships that were positive and equal collaborative partnerships promoted recovery. On the other hand, participants in both studies said negative messages from staff, controlling staff, and poor quality psychiatric services were barriers. Crisis assistance and hospitalization were mentioned as important to some informants in each study. In addition, participants in our study wanted the opportunity to receive services prior to getting into crisis, pre-empting possible deepening of symptoms. They also emphasized having alternatives to hospitalization.

Competency, empowerment, sense of personal control, and the right to make choices and take risks were other factors important in both studies. The need for recovery-oriented systems to increase understanding of the disorder, educational resources, and reduced reliance on medication as the single tool for addressing the disorder, were mentioned in both sets of findings. Both studies found medication to be important, but medication and side effects were also viewed as barriers by participants in both studies. The importance of social processes including support from family, sociality, friendship, self-help and mutual assistance, support groups, and spirituality were also important themes. Having hope, meaning and purpose, something to look forward to, and meaningful activities were found to foster recovery in both studies. Many of our participants elaborated that paid and volunteer work have multifaceted benefits (not simply therapeutic).

Young and Ensing (1999) conducted seven semi-structured qualitative interviews and a focus group involving a total of 18 people, and used grounded theory to explore the meaning of the recovery process. A portion of the data from that study discusses recovery strategies and factors that promote recovery. All of the extensive findings of the Young and Ensing study were also found in our focus group data. Some highlights of shared findings include the importance of assumption of self-responsibility for managing one's disorder; self-monitoring of symptoms; pulling back from destructive habits; developing empowering attitudes; the importance of learning and risk-taking; recapturing parts of the old self and discovering new aspects of one's being and learning that there is more to the self than the illness/disorder; self-care, including concern for meeting basic needs; improved functioning; medications; being active, vocational activities and exercise; and connecting with others including consumer friends, family and the community. Improving one's sense of well-being in the Young and Ensing study included such things as improving self-esteem, feeling "normal" or stable and caring about things. Other shared findings include the importance of spirituality, meaning and purpose, maintaining a positive focus, being creative and working. Improving one's standard of living, including having nice housing and a car, supported recovery.

In our study at least a portion of people relate an abiding awareness that there is more to the self than one's illness/disorder. But they note as well the ways in which the larger environment can undermine one's efforts to move beyond a disorder view of self—for example, how the orientation of formal services and stigma/discrimination can contribute to a

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diminishing view of oneself as a whole person. Our participants also clarified that the value of connecting with others, including family and community members, was something that includes the notion of free association based on preferences and the quality of experiences. Within our study, the meaning and role of spirituality differed among participants. It is also important to note that maintaining a positive focus was helpful to some in our study but was not necessarily a shared outlook.

Research conducted in Ohio by Smith (2000) presented information drawn from extended qualitative interviews with 10 people. Smith looked at the definition of recovery and the personal process of recovery, and when recovery begins. Other parts of Smith's study examined the strategies people used to recover—factors crucial to achieving recovery as well as barriers to recovery, which will be discussed here. Smith found recovery to be a complex process. Themes in her study included the importance of having positive goals, the need for determination and staying with recovery over a long period, a sense of control, and independence. These factors are reflected in our study data, the one caveat being that we surmise that staying with recovery over a long period is what participants strive toward.

Finding the right helper/psychiatrist, having consistent helpers, having a positive relationship with helpers, and taking the right medications were found to help recovery in both studies. Smith found that having positive relationships with peers, family, clergy, consumer and non-consumer friends, having a group of supportive people around you in general, and involvement in positive social activities helped recovery. These findings concerning the importance of relationships and social connectivity were mirrored in our focus group data. Having a positive structure to one's life and participation in other meaningful activities (work that meets one's preferences, church, community clubs, self-help inside and outside the mental health system, participation in consumer-run services, etc.) were other important themes in both Smith's study and the current research.

Sense of control and independence, believing recovery is possible, self-respect, self-responsibility, taking care of the physical self, and having a positive outlook and appreciation for life were identified as helping recovery, as were the importance of opportunities and resources that would help one to be "a complete whole person" (Smith, 2000, p. 151). These findings closely mirror those of the "Helps" aspects in the self/whole person findings in our focus group data. Acceptance of disability was viewed as crucial for those in Smith's study, and received some attention in our focus groups.

Hindering factors found in both studies included substandard housing, being on the wrong medications, medication side effects, being served by unresponsive helpers, personal factors of poor self-esteem, symptoms of the disorder and vulnerability to stress, lack of financial resources, and limited access to needed services. In both studies, stigma—including media images and internalized stigma—was found to be a hindering factor that one needs to struggle to overcome.

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A recent Scandinavian study of 17 fully recovered persons who had been diagnosed with schizophrenia, conducted by psychologist Anne-Karen Torgalsboen (2001), examined what people said was helpful in their treatment as well as other factors that promoted recovery. Only a small proportion of those studied were on psychiatric medication, and only one person among those studied believed meds to be very important to their recovery. Participants stressed their own willpower and intellectual strength, religious belief, solidarity with co-patients, knowledge gained about the disorder, and the structure of hospitalization were all important to recovery. Positive qualities in their helpers was the most mentioned factor (most received psychotherapy). The characteristics found in recovery-facilitating helpers are consonant with findings of the current study—these qualities included an attitude of equality, unconditional acceptance, understanding and empathy, and confidence on the part of the helper. Knowledge and up-to-date information were stressed in our study as adjuncts to these helping qualities.

In summary, the Phase One findings of the *Mental Health Recovery: What Helps and What Hinders?* project confirm and in many cases extend the findings of earlier qualitative research with similar research aims, most of which had small numbers of consumer informants. In addition, the current study provides a unique contribution to existing research with its multi-site nationwide sample of public mental health service clients. Clearly, studies that examine only helpful elements miss important information on factors that serve to impede recovery. A small but growing knowledge base is converging that can inform the field about processes and factors that encourage or hold back personal recovery. Recovery findings indicate that consumers share important knowledge that can be used to encourage a broader recovery orientation.

### **Explication of Phase One Findings**

Recovery is very complex, making it difficult to delve into all the aspects of the recovery process in depth. We are able to discuss only a fraction of the complexity we found in the focus group data. The presentation of our findings is somewhat linear, and does not fully capture the dynamic interactions that occur across domains and the dynamic experience of recovery. Themes are not neatly separable, but rather are interconnected in important ways. We have come to understand that recovery is contextual or ecological; it is shaped and impacted by personal, social and physical environments.

A conceptual paradigm for organizing and interpreting the phenomenon of mental health recovery is beginning to emerge from the study findings. This paradigm maintains that recovery is a product of dynamic interaction among characteristics of the individual (the self/the whole person, hope/sense of meaning/purpose), characteristics of the environment (basic material resources, social relationships, meaningful activities, peer support, formal services, formal service staff), and the characteristics of the exchange (hope, choice/empowerment, independence/interdependence). This emerging paradigm is integrative and holistic, (i.e., focusing on the whole person functioning in his or her environment) while acknowledging the interrelations, multiple dimensions, individuality and



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complexity of the recovery phenomenon. Within this paradigm, mental health recovery is located on a continuum and suggests the need for an applied social model that can account for the interrelationship of complex environmental factors (families, immediate environments, various systems, public policies, culture, and society), personal characteristics (responsibility, resourcefulness, reliance, self-care, purpose, spirituality) and the nature of the exchange (empowerment, respect, authenticity, partnership) on such factors as participation, productivity, involvement, quality of life, and psychological adjustment of the individual. Past conceptualizations of mental health recovery largely ascribe recovery to the individual and underplay the interaction, interconnection and exchange that occurs between the environment and the individual.

Within this ecological context, one dimension of recovery requires attention to “basic material needs.” When basic material needs are met in a stable and reliable fashion, a sense of safety is created. The establishment of safety is the starting point for healing (Bloom & Reichert, 1998). As emphasized in participant comments, having their basic human needs met—a livable income, safe and decent housing, health care, transportation, a means of communication (e.g., telephone)—moves people towards recovery. Poverty and the lack of basic resources undermine a sense of safety and hold people back in their recovery.

Along with basic material needs is the need for the opportunities and supports necessary to engage in the responsibilities and benefits of citizenship. Citizenship is defined as membership in a community (*Webster’s Dictionary*, 1984). Recovery involves this social dimension—a core of active, interdependent social relationships—being connected through families, friends, peers, neighbors and colleagues in mutually supportive and beneficial ways. Participants recounted how supportive and accepting personal, social and intimate relationships and open communication contribute to the recovery journey, often serving as a source of mutual aid. In a sense, participants are describing the shared experience of creating and maintaining safety through mutually supportive relationships. Participants also recognize that freedom and citizenship entail the possibility of hazards or risks, but that positive connections can act as buffers in such situations. Social and personal isolation, poverty, emotional withdrawal, controlling relationships, poor social skills, immigrant status, disabling health and mental health conditions, past trauma, and social stigma impede the recovery journey.

Full citizenship expands beyond social relationships, however, and incorporates civil rights and responsibilities. Participants indicated that recovery is enhanced through engaging in meaningful activities that connect one to the community. Often this can be achieved through a meaningful job and career, which can provide a sense of identity and mastery. Participants also identified other options, such as advancing one’s education, volunteering, engaging in group advocacy efforts, and/or being involved in program design and policy level decision-making. The current reality is that such involvement is greatly restricted. Participants report high rates of unemployment, underemployment, and exploitation. Training and education opportunities are lacking, benefits have employment disincentives, prejudice and discrimination hamper efforts and individual wishes and decisions are disregarded.

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When considering the basic material needs, social and citizenship dimensions to recovery, we are struck by how generic and universal the responses were to what might be expected from almost any group of American adults. Safety, an adequate income, a secure job, a decent home, friends, family (or constructing one of your own), intimacy, and community involvement constitute what one could view as a compelling belief in the “American Dream” of economic opportunity, self-sufficiency, liberty and the pursuit of happiness.

Our findings support how personhood serves as another critical dimension of recovery. Participants talked about the internal sense of self, inner strivings and their whole being (physical, emotional, mental, and spiritual) as affected by and affecting the recovery process. They described various personal qualities, attitudes and conditions that can help (self-reliance, personal resourcefulness, self-care, self-determination, self-advocacy, holistic view) or hinder (not taking personal responsibility, shame, fear, self-loathing, invalidation, disabling health and mental conditions).

The personhood dimension is also about hope, purpose, faith, expectancy, respect and creating meaning. Participants described how developing a sense of meaning, purpose and spirituality as well as having goals, options, role models, friends, optimism and positive personal experiences support recovery. Demeaned dreams, pessimistic staff, poor quality services, discounted spirituality, poverty, unwanted and long-term psychiatric hospitalization, and lack of education and information about one’s condition and potential resources destroy hope and act as roadblocks to recovery. All have powerful negative effects on individuals’ self-concept, esteem and sense of efficacy. These effects are compounded by mental disorder itself and the associated stigma (internalized and external), prejudice, and discrimination. The concept of engulfment is helpful in understanding how a person’s self-concept is transformed by the experience of mental illness. Role engulfment occurs through progressive role constriction in which people successively lose valued social roles until only a chronic mentally ill identity remains (McCay, Ryan, & Amey, 1996). In some instances role constriction and a chronic mental illness identity occur before a person has attained certain valued social roles, such as a job or career, educational attainment, and parenthood.

Believing that recovery is possible and having this belief supported by others (friends, family, peers and staff) helps fuel self-agency (the process of intentionally living one’s life on one’s own accord) and avoid role engulfment. Our findings lend support to this critical role of self-agency, a core element in recovery and in the personhood dimension of recovery. Participants as “self agents” and taking self-responsibility for the direction and management of healing were discussed across focus groups. Analysis of such comments reveals how qualities within the personhood dimension pose strengths and difficulties. In tandem they may have an intensifying effect on self-agency. Building on strengths and dealing with or minimizing weaknesses involves self-awareness, knowledge building, belief and action. Participants want to understand what they are experiencing, they want to be educated, have good information and actively participate in making important choices. It is also important to note that some of our findings seem to indicate that certain cultural affiliations, such as tribal

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community, may modify the emphasis on self-agency through activating kinship or tribal mores that stress interdependency or living for the good of the larger social unit.

It is important to keep in mind that our research study deliberately shifted the focus from personal process to contextual or ecological—allowing for the personal but emphasizing the social and physical environments. Existing mental health recovery literature tends to focus on the individual process of recovery, often described as a series of stages. Ralph and The Recovery Advisory Group (1999) describe these stages as anguish (bottoming out), awakening (the turning point), insight (beginning of hope), planned action (finding a way), determined commitment (to get well), and well-being and empowerment (to help self and others) in relation to external influences. Young and Ensing (1999) report “a process of 1) overcoming ‘stuckness,’ 2) discovering and fostering self-empowerment, 3) learning and self-redefinition, 4) returning to basic functioning, and 5) improving quality of life” (p. 222). Both sets of authors also acknowledge that these stages are not all inclusive of the stages a person may be experiencing, nor does each person necessarily experience all these stages or move through them in a linear fashion.

Although not the focus of our inquiry, our analysis of the focus group transcripts also reflected engaging in such stage-wise processes. Specific examples follow. “If I gain an inch, I’m doing all right. I’m not hoping to gain a foot or a mile. I’m looking to gain that inch” (TX 1852).

All the cultural messages that we get is that this is devastating and life-ending and life, as you know it, is over, and you’re going to be relegated to some sort of mediocre subsistence level and it’s just all damaged and all lost and all waste, and rejecting that, and deciding that this was as much as an opportunity for growth and for change and for learning to see what worked and what didn’t work (RI 441).

“Coming to this point where I am saying, ‘Yeah, I can see a road, and there’s a future’ (TX 732).” Actively engaging in the process of change as described in these comments (reframing and finding alternative paths and perspectives) seems to be an element within the personhood and self-agency dimension of recovery.

When considering the fullness of the personhood and self-agency dimension to recovery, we are again struck by how such findings speak to universal quality of life needs and desires. Participants’ life journeys began prior to the onset of mental illness and continue after. Hope is a major factor in advancing participants’ life journeys. Thus, a holistic focus and positive expectancy (regarding attitudes, beliefs and goals)—on one’s own part, on the part of helpers, within families, and in the media and the broader community—can move recovery forward.

For change to occur another critical dimension of recovery must be in place, that of empowerment. A great deal of attention in the mental health literature has been paid to

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disempowerment or the deficits that result from a perceived lack of control (see Garber & Seligman, 1980). But starting in 1981, Rappaport helped to focus attention on the importance of empowerment. The word empower, in reality, implies taking control, or people gaining control of their own destiny (Condeluci, 1991). It's a process of "gaining control over one's life and influencing the organizational and societal structure in which one lives" (Segal, Silverman, & Temkin, 1995, p. 215). Zimmerman and Rappaport (1988) have explored this relationship between a sense of personal control and the willingness to take action in the public domain.

Restated, empowerment consists of a process of increasing personal, interpersonal, and/or political power so that individuals can take action to improve their life situation (Gutiérrez, 1990). Having power means being informed and selecting a course of action from among multiple, meaningful possibilities and implementing that course through access to resources (Miley, O'Melia, & DuBois, 1995). The goal of empowerment becomes one of people gaining power and control over their lives through access to meaningful choices and the resources to implement those choices. Zimmerman (1990), for example, found a direct effect of participatory decision-making on psychological empowerment.

Our findings document the crucial role that choice plays in empowerment. Having information on, and access to a range of meaningful and useful choices and options fosters recovery. Participants are empowered when they make the choices regarding where they live, housing, finances, employment, personal living/daily routine, disclosure, who they associate with, self-management and treatment. Individual participants talked about the empowering experience of choosing "how I see myself, my disorder, my situation, my quality of life." But for such empowerment to occur, meaningful options must exist and people must have training and support in making choices, as well as the freedom to take risks and fail. Quality of life choices seemed too often outside the realistic reach of many participants. Options are limited, ineffective or nonexistent. Participants recounted service providers, professional and family members, and communities that responded through the use of coercion, control, restricted access or involvement, discrimination and stigmatization.

Independence—not being subject to the control of others and not requiring or relying on others (*Webster's Dictionary*, 1984)—also falls within the empowerment dimension. Participants expressed it as both a process and goal of recovery. Independence is achieved through making one's own choices and decisions, exercising self-determination (such as advanced directives), enjoying basic civil and human rights and freedom, and having a livable income, a car, affordable housing, etc. Paternalistic responses, lack of respect, involuntary and long-term hospitalizations, stereotyping, labeling, discrimination, the risk of losing what benefits and supports one does have, all undermine independence. Repeated encounters with such experiences instill fear, lack of confidence, and negative attitudes and beliefs.

Some participants talked of the importance of both independence and interdependence, reaching beyond the goal of independence to that of embracing interdependence.

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Interdependence is a term that implies an interconnection or an interrelationship between two entities and is used to describe the link of people to people.

In a new sense all life is interrelated. All persons are caught in an unescapable network of mutuality, tied to a single garment of destiny. Whatever affects one directly affects all indirectly. I can never be what I ought to be, and you can never be what you ought to be until I am what I ought to be. This is inter-related to the structure of reality (Martin Luther King, Jr. as cited in Condeluci, 1991, p. 88).

Seeking independence and interdependence are not mutually exclusive. Participants who talked about the importance of independence in their lives also talked about the importance of relationships, giving and getting support particularly from peers. Participants emphasized being the decision maker while valuing input from others. They stressed the role of needing others and being needed yet ultimately relying on oneself. Formal services and staff were seen as helpful when they fostered partnership, mutuality, and exchange, and they were seen as hindering when they exerted undue control. Interdependence is about relationships that lead to a mutual acceptance and respect. Participants want respect as fully independent adults even as they may open themselves to the “critique” of others, sharing some of their decisions and choices with particular individuals on the path to recovery.

Linking to the dimension of empowerment through the notion of interdependence is the critical role of referent power. Shared experience, equality of role relationships, similarity of goals and tasks help generate referent power, the power of the referent source to motivate and influence the individual based on an understanding of and support for the individual’s ongoing struggles (French & Raven, 1959; Janis, 1983; Raven, 1992). The mental health self-help and consumer/survivor movement provides referent power opportunities.

The need for a large-scale expansion, funding, support and availability of peer services, such as peer support, education, outreach, role models, mentors and advocates was a common theme across focus groups in all nine states. Participants identified the need for alternative services and “experienced experts/peer specialists” employed across all levels of mental health service provision. Lack of funding, infighting over limited funds, very limited geographical availability (limited to urban areas), limited participation, limited leadership development opportunities, lack of transportation, and controlling and mistrustful professionals hinder peer support efforts.

The formal service system, and the professionals and staff employed within it, constitutes another dimension that impacts recovery. We clearly see that progress toward recovery can be supported through the formal system. However, our data contained much more “hindering” content regarding formal systems than any other domain.

We must fully acknowledge that the formal system often hinders recovery through bureaucratic program guidelines, limited access to services and supports, abusive practices,

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poor quality services, negative messages, lack of “best practice” program elements, and a narrow focus on a bio-psychiatric orientation that can actually serve to discount the person’s humanity and ignore other practical, psychological, social, and spiritual human needs. Often these hindering influences are the unintentional consequences of procedures implemented by well-meaning authorities in a belief that the practices are in the best interests of patients. Many of our findings lend further support to shortcomings already identified within the formal system of care. People have basic subsistence needs that “the safety net” does not meet. Social welfare and mental health programs are fragmented and difficult to access. People do not want to have to deteriorate in order to receive help, nor do they want to lose vital supports when they make progress toward recovery. Psychiatric services often are experienced as a means of social control, countering individual efforts of recovery.

At the core of the hindering forces within the formal service system is the operationalization of society’s response to mental illness—that of shame and hopelessness and the need to assert social control over the unknown and uncomfortable. “[T]he label of mental illness is so pervasively negative and has such devastating social consequences that anyone who can escape or deny it most likely will do so” (Kaufmann & Campbell, 1995, p. 10). People with severe mental illness contend with multiple and recurring traumas (e.g., the mental illness itself; side effects of medication; negative professional attitudes; devaluing and disempowering programs and practices; loss of sense of self, social roles, and personal relationships; restricted or denied rights, opportunities and self-determination; and rejection, discrimination, and stigmatization). People with mental illness “are left profoundly disconnected from themselves, from others, from their environments and from meaning or purpose in life” (Spaniol, Gagne, & Koehler, 1999, p. 411). Giving up becomes the solution. Hopelessness, apathy, helplessness and indifference become strategies that desperate people adopt in their silence to stay alive (Deegan, 1996).

The experience of trauma and abuse was also notable across the focus groups. The impact of the status of the mental health patient comes through in our findings—through the discussion of internalized stigma, the repeated traumatizations by the system, and the historical trauma of past abuse. The formal service system and many of its personnel largely overlook how responding to, and coping with, trauma is a central experience of psychiatric disorder and thus they fail to incorporate trauma knowledge in existing explanations of, and responses to, mental illness. To paraphrase Bloom and Reichert (1998), we must change the fundamental question from *What's wrong with you?* to *What's happened to you?* It is possible to establish with the formal service system a culture to counteract the personal and systemic effects of trauma. Such efforts would entail developing a culture of belonging, safety, openness, participation, citizenship and empowerment (Haigh, 1999).

Pivotal in creating such a culture is the large-scale support of peer services and peer staff, both independent of and integrated into existing service delivery systems. Fundamental in coping with mental illness is regaining a sense of belief in oneself (Chamberlin, 1997). But when faced with severe and multiple traumas—with denial of rights, inferior and abusive treatment, substandard living, denied and severely limited quality of life opportunities—

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regaining a sense of belief in oneself can seem beyond reach. It is possible though, by finding empowerment in each other (Walsh, 1999). This empowerment includes consciousness-raising, validation of experience, constructive anger/defiance, advocacy for self and others, acceptance of responsibility, a sense of free will, and confidence (Ralph, 1998).

Another critical change involves the need to return to the basic core of helping—the need for positive helping relationships based on partnership, a “therapeutic alliance.” People do not want to interact with neutral, detached helpers, nor do they want to meet a new professional or paraprofessional each time they seek help. Opportunity for choice and negotiation in selecting partnership relationships with a doctor, therapist, or case manager were strong concerns. Similarly, the collaborative development of an individual treatment plan with full medication information on potential benefits and side effects was also a strong concern. Most persons sought to continue to be in charge of their treatment or recovery plan to the maximum degree possible and to exercise choice in all aspects of their lives, sometimes through the use of mental healthcare proxies or advance directives. They want to have people care for them and listen to them and empower them. Respect for and as an individual stands out—the whole focus of the helping relationship should have this value at its core—as the actualization of the individual through self-determination and choice.

Recovery can be construed as a paradigm, an organizing construct that can guide the planning and implementation of services and supports with people with severe mental illness (Spaniol et al., 1999). The outlines of a new recovery-enhancing paradigm system are emerging. Such a system is person-oriented, and respects people’s lived experience and expertise. It promotes making choices and self-responsibility. It addresses people’s needs holistically and contends with more than their symptoms. Such a system meets basic needs and addresses problems in living. It empowers people to move toward self-management of their condition. The orientation is one of hope with an emphasis on positive mental health and wellness. A recovery-oriented system assists people to connect through mutual self-help. It focuses on positive functioning in a variety of roles, and building or rebuilding positive relationships.

The paradigm shift into recovery occurs by clearly identifying what consumers/survivors hope for and dream of achieving, capturing these thoughts in their own words, and then individually tailoring services and supports to help each consumer achieve his or her dreams. A system of care that “fosters recovery must be one in which hope is an essential component of each activity” (Walsh, 1999, p. 60). Such a system strives to implement the ideals of a recovery orientation as compared to the focuses of the old paradigm or chronicity orientation, as detailed in Table 3 (Ridgway, 1999; Ridgway & Onken, 1999).

**Table 3: Chronicity versus Recovery Paradigms**

<b>The Chronicity Paradigm</b>	<b>The Emerging Recovery Paradigm</b>
Diagnostic Groupings; “Case”; Lumped and Labeled as “Chronics”/ SPMI/ CMI	Unique Identity; Person-Oriented; Person-First Language
Pessimistic Prognosis; “Broken Brain”	Hope and Realistic Optimism
Pathology/ Deficits; Vulnerabilities are Emphasized; Problem-Orientation	Strengths/ Hardiness/ Resilience; Self-Righting Capacities Emphasized
Fragmented Biological/ Psychosocial/ Oppression Models	Integrated Bio-Psycho-Social-Spiritual Holism; Life-Context
Professional Assessment of “Best Interests” and Needs/ Paternalism	Self-Definition of Needs and Goals/ Voice/ Consumer-Driven/ Self-determination
Professional Control/ Expert Services	Self-Help/ Experiential Wisdom/ Mutuality/ Self-Care/ Partnering with Professionals
Power Over/ Coercion/ Force/ Compliance	Empowerment/ Choice
Reliance on Formal Supports or “Independence”	Emphasis on Natural Supports; Interdependency
Social Segregation; Formal Program Settings; Deviancy-Amplifying Artificial Settings	Community Integration; “Real Life” Niches; Access & Reasonable Accommodation to Natural Community Resources/ In Vivo Services and Supports
Maintenance/ Stabilization; Risk-Avoidance	Active Growth/ New Skills & Knowledge/ Dignity of Risk
Patient/ Client/ Consumer Role	Normative Roles/ Natural Life Rhythms
Resource Limitations/ Poverty	Asset Building/ Opportunities
Helplessness/ Passivity/ Adaptive Dependency	Self-Efficacy/ Self-Sufficiency/ Self-Reliance

We gained much information from participants during the course of this research, but in many ways we have just scratched the surface. Apparently, there are cultural influences in how the recovery journey is made and in how the self is experienced. We were impressed, for instance, by a First Nation tribal member who drew on community and healing traditions to support recovery. But with only a small number of people from ethnic and racial minorities we only saw a glimmer of these processes. Other examples are listed below.

- ◆ **Regional Differences:** Some places see very little or no change in services over the years and other areas of the country embrace constant change and progress; some participants prefer the anonymous nature of urban life while others prefer small towns where people know you.
- ◆ **Cultural Differences:** Does the concept of self-agency play as strong of a role in Native American culture, where tribal and community support is so strongly emphasized, a wrap-around of support towards recovery? How does culture influence recovery within



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Hispanic/Latino American and Asian American individuals and communities, where family may assume a more central role?

- ◆ Immigrant Status: How does the experience of immigrant status (living with few resources, language and cultural barriers, INS requirements, etc.) influence seeking help and recovery?

### **Study Limitations**

Focus group methodology performs well at generating many ideas in a short period of time. It does not allow us to identify the extent of consensus on these issues, nor can we determine which ideas or domains are most or least important. We have presented the data without trying to create a hierarchy of “most important” or “least important” factors. How many people share all or most of the views included in the findings is a question that qualitative studies do not answer.

The research design incorporated a purposive sampling strategy in an attempt to recruit and engage a widely diverse group of participants, thus the 115 participants are not intended to be seen as a nationally representative random sample. The 115 focus group participants did reflect a broad range in such demographic characteristics as community size, education, monthly income, sexual orientation, marital status and parenthood. The sample composition, however, was disproportionately female and middle age (40-59). There were very few participants who were young, who identified as Hispanic/ Latino or Asian, or who spoke a language other than English at home (an indication of immigration and assimilation status). These recruitment shortcomings may be interconnected, as the proportion of Hispanic/ Latino people is highest in younger age brackets and the proportion of Hispanic/ Latino and Asian people is high in current immigration patterns. Such participation was also limited by lack of funds to facilitate participation in languages other than English. This lack of representation of age, ethnic and cultural diversity limits the extent to which this study uncovered cultural and age-related variations in mental health recovery.

The recruitment process in all states entailed self-selection and actively involved each state’s MHA. Kaufmann and Campbell (1995) have raised the issue of distorted representation—either through tapping into the consumer elite or the subgroup of people with mental illness that providers recruit. At least 75% of the participants reported being or having been involved in consumer/survivor organizations. Such involvement increases the likelihood that many of the participants have exposure to and involvement in mental health recovery thinking, issues and strategies. The vast majority of consumers who are recipients of public mental health services, however, are not affiliated with consumer organizations, self-help and/or the mental health consumer movement (Chamberlin, 1990). The very small number of participants that reported residing in supervised living situations or boarding houses (7) or being homeless (1), further indicates that the sample is not fully representative of the population of public mental health system recipients.

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Depending on the state, participants included known consumer leaders, advocates, or representatives. It is most often these consumers who serve as key informants when consumer input is sought in the planning, delivery and evaluation of public mental health services (Kaufmann & Campbell, 1995). Though participants reported a range of self-identified psychiatric diagnoses and most reported having been hospitalized for psychiatric reasons, there was a predominance of mood disorders. This predominance of mood disorders reflects at least in part the prevalence of diagnoses of mood disorders. Preliminary research indicates that consumer leaders, advocates, or representatives tend to self-identify mood disorders more often and that their perspectives, depending on the nature of the inquiry, may differ from those who self-identify other psychotic disorders such as schizophrenia (Onken, 2000).

Optimal size of focus groups is generally considered to be 6 to 8 participants (Krueger & Casey, 2000). The research design encouraged 8-15 participants as there were limited resources to conduct multiple smaller-size focus groups. All but one group exceeded 8 participants, some were twice the optimal size. The larger sizes may have limited individual participant opportunities to share insights and observations (Krueger & Casey, 2000), possibly limiting the potential for synergism within a group. Participants' contributions constituted a one-day snapshot of life issues that for most were derived from many years of experiences, with and without mental health services. This temporal nature of the research contact limits contributions and influences findings.

The wording of Question Set #6 was designed to elicit how mental health staff or services have helped or hindered recovery. The lack of specific attention to mental health staff or services in Question Sets #1-5, however, did not preclude participants discussing contributions of the mental health system regarding these questions. Advice for decision makers was sought in Question Set #7 to identify particular activities that should be implemented, modified or discontinued in order to facilitate recovery. Therefore participants moved from the reality of what exists to their own ideal of what should be. Though not a limitation in the research, the feasibility for realizing some elements of the ideal as voiced by the participants would require reprioritization and restructuring of current services.

Temporality, as noted above, is also a limitation regarding the member check process, which was conducted several months after the groups were held. In addition, factors such as discontinued telephone numbers and change in residential locations influenced the member check response rate. Given these challenges, the 51% response rate can be viewed as quite high.

## **Implications**

The work of Phase One of this project constitutes a rich and complex fabric of findings for use in formulating future research, including the construction of evaluation tools to examine mental health system performance as to how well local and state mental health systems promote or facilitate mental health recovery. Study findings also extend our understanding of

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recovery beyond the boundaries of traditional service systems. Focus group participants contributed their lived experience and knowledge concerning the full range of systems and ecological factors that have helped or hindered the process of recovery in their lives. Thus, the findings of this study are relevant to public and private mental health constituencies, mental health consumers and their allies, and the public at-large.

While recovery is in part based in self-responsibility and self-agency, clearly many other factors have an impact on the recovery process. The ecological perspective that helped frame this study, which focuses upon a person in active interchange with the social and physical environment, was supported in study findings. It is clear that the way we configure mental health and social service policies, formal mental health services and the day-to-day informal cultures that exist within programs and systems can serve to either promote or inhibit recovery.

The study reveals that recovery is generally not an individual, solitary process of a lone person triumphing over adversity. Instead, recovery is based upon a dynamic interplay among a complex set of forces that includes the person in an interchange with other people, the resources available in the environment, and other forces that range from the content of media messages to intangible and tangible spiritual resources. In fact, recovery is shown to be a social process that involves positive relationships, interpersonal support, mutual assistance, church communities, families, intimate partners, friends, and involvement and a sense of place within many small and large communities.

Many people use and appreciate formal treatment including clinical services and medications. The dominant story that medications are the basis for recovery and that people must remain on medications for life, however, has a counterpoint in this study and other similar research. Some people recover without formal services and some do not require medication. Others warn that the trade-offs for taking medication become crucial and difficult choices. While some participants said compliance with doctor orders aided recovery, others told of languishing for years on heavy or ineffective drugs.

People described many other strategies beyond or in lieu of medications that improved their mental health. Strategies shared include development of coping skills, wellness recovery action planning to stay well and contend with triggers or crises, attention to their strengths, cognitive techniques, stress reduction activities, holistic approaches, and general wellness, including exercise and nutrition. A shift to a recovery orientation will require attention to wellness and health promotion, not simply attention to symptom suppression or clinical concerns.

While the *Mental Health Recovery: What Helps and What Hinders?* project is based in the desire and mandate to move mental health systems to a recovery orientation, we are just beginning the long process of change to achieve that result. Many consumers have little access to quality services and the kinds of relationships and basic supports that would make recovery a greater reality in their lives. Many systems, including some in this study, lack a

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semblance of a recovery-orientation. We are just beginning to see the outlines of what such a system would look like. It seems participants in many of the focus groups were much more able to envision desired elements of an ideal system, than were able to point to existing elements of the current system and services that worked well for them and strongly supported their personal recovery.

It is not surprising that consumers participating in focus groups around the country spoke eloquently about concepts associated with American citizenship or the American Dream. Self-determination, liberty, the optimal exercise of personal choice, privacy, a safe home, good health, independence in decision-making, a livable income and a sense of connection within a community are fundamental aspects of our rights and desires as a people. What is perhaps hard to understand at this time is how often people contending with psychiatric disorders or disabilities are denied these fundamental rights and opportunities. A recovery orientation will require close attention to such fundamental rights and needs.

Participants in several groups called for a fundamental shift away from coercion and social control toward respect for liberty. Some systems are attempting to make such a shift. Re-orientation away from coercion requires alternative resources as well as training. Participants suggested ideas such as advance directives to protect their rights and promote their choices while they are in crisis.

The methods used in this study (i.e., grounded theory) help build knowledge from the grassroots or “ground up.” It can help us identify both common thoughts and divergent viewpoints. It is quite apparent that a great deal of convergent thinking exists on fundamental or core aspects of what helps and what hinders recovery. We see this when examining data across the groups, and when triangulating findings with other studies that listen to the voices of people who are living the process. Many more common threads than differences exist. We must be open though, for a continual evolution in our thinking, and for development of knowledge concerning recovery among diverse communities. For example, the balance of autonomy and self-reliance versus group or family focus may differ in recovery based on such factors as ethnicity and culture. Special attention is needed for people who have experienced trauma or who have substance use disorders.

We are just beginning to develop a shared language and understanding of recovery. Participants in the focus groups called themselves consumers, recipients, ex-patients, survivors, or patients, and they self-reported many diagnoses. In more and more instances, we are putting the person first and seeing people as unique individuals with hopes, lives, strengths and dreams. While each participant may be “a person with mental health problems,” they shared their deep humanity—their experiences, stories, humor and wisdom. People are re-claiming much broader understanding of themselves beyond their labeled identity.

Findings in the study show us just how important language is in relation to recovery. Negative and erroneous messages from helpers, experts, media and the public about limited

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potential wound and hold back recovery. On the other hand, more positive messages, stories of healing, and the potential for growth shared in the media, among families, in support groups and fostered by helpers allow people to flourish and evoke our potential for resilience.

Our study shows the great need for educating one another and our communities. Resources for re-educating families, consumers, the professions and paraprofessional providers, young people, and the public at-large on the potential for recovery are needed, and will take significant investment. Stigma and misinformation must be countered through a variety of strategies (with attention to incorporating active roles for consumer/survivors) and targeted to many audiences.

Our data show many people want to live interdependently, with strong circles of support made up of their spouse/partner and children, other family members, peer supporters and friends, and they want to live within safe, decent, affordable housing integrated into communities while earning livable wages in meaningful jobs. Many mental health systems have retreated from the development of practical supports or community support systems. Without attention to basic needs in safety, housing, healthcare, income, employment, education and social integration (including the education, involvement and development of natural supports such as family members) some systems neglect core circumstances that can foster recovery.

Study findings contain many other areas of complexity. For example, hope has been viewed as a core element for recovery in many writings. In our study, participants had differing views of hope. For some, hope, positive expectations, positive role models, belief in a higher power or in their own resilient will to survive, are the prime forces underlying their recovery journey. For some others, hope has been repeatedly unfulfilled, and a positive outlook rings false as a counterfeit promise. Another complex issue is the relationship between empowerment and recovery, a strong finding in our study. Both areas (i.e., hope and empowerment) warrant further research attention.

Participants reported that consumer participation in treatment planning was given lip service by providers but was seldom practiced in a meaningful manner. Nevertheless, many consumers believe that the quality of services can be improved through increased democratic involvement of consumers in not only treatment planning, but in policy and program development and evaluation as well. True parity of decision-making power and respect through mutual and supportive partnership among consumers/survivors, professionals, administrators and policy makers can become the basis of collaborative efforts to design and implement action strategies that will move America's mental health systems toward a recovery orientation.

We have learned a great deal from listening to the experiences and wisdom of the consumer participants. Several of the State Mental Health Agency staff members who worked on the focus groups, transcript preparation and/or member checks expressed gratitude for the wealth of knowledge shared by the participants as well. One of the fundamental assumptions

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shaping this study was that the lived experience of recovery was crucial in understanding, reshaping and reforming mental health systems at this time of a profound shift toward a recovery orientation. We cannot stop listening to the voice of experience. Suggestions made in the focus groups for increasing the voice of consumers merit attention. These recommendations included hiring many more consumer providers and state office officials with the direct experience of recovery, increasing consumer presence on advisory committees and governing boards, having consumer-run services, peer advocacy and peer support opportunities, as well as having consumers train staff. Adequate resources are needed to fund and support consumer voice and consumer leadership development.

### **Next Steps**

The long-term goal of this research project is the development of a core set of systems-level indicators that measure critical elements and processes of a recovery-facilitating mental health service environment. In Phase Two of this work, the findings of Phase One will be utilized to comprise a set of prototype performance indicators. In Phase Three the resulting measure will be pilot tested across multiple sites.

More specifically, in Phase Two the research team will select topics to be developed into survey items and Information Management Systems (IMS) data indicators incorporating the findings of the Phase One Report and the member check ratings of priority themes. The Phase One themes and findings will provide the foundation for the content and emphasis for the indicators. Existing literature and other current mental health system performance measurement development efforts will help inform this effort. The team will formulate topics into survey statement items and IMS indicators. The team will refer back to the unique concepts or natural meaning units for possible specific wording and clarification of intent. With themes, returning to the actual context may be particularly important. For example, medications can play a helping or a hindering role in recovery. A closer examination of context may reveal that it is the right combination of medication that facilitates recovery. We might word an item to get at this concept as, “I receive medication in the right combination for my illness.”

As each indicator takes shape through revisions and edits, the team will select appropriate response scales (e.g., frequency, agreement, or valuation) and identify the source of response. Consumer self-report is one component, but there may be other data sources that can also be tapped when evaluating a system’s responsiveness to some of these indicators. Although the team plans largely to abstract from the findings and member check results of Phase One, some items from existing instruments may be applicable. The team will seek key stakeholder review and feedback as to clarity, understandability and priority (considering such elements as significance, relevance, and burden) of the indicators. This review will be particularly important for administrative data source indicators. A member check with sub-sample of consumers/survivors will then be conducted.

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Once this feedback process is completed, the research team will proto-test the resulting item set and indicators. This process will include a “think aloud” session with consumers/survivors, refinements based on feedback from the think aloud session, and then a pilot survey of 100 consumer/survivor respondents. The pilot survey will yield data allowing for analysis and interpretation of survey items (e.g., assessing Chronbach’s alpha for internal consistency, etc.), resulting in further refinements.

The resulting core set of indicators will be incorporated into short form recovery orientation measures for combination with existing instruments and a long form stand-alone instrument. Performance on the measure is expected to be objective given the multiple sources, reviews and refinements. It is important to keep in mind that the resulting performance indicators will be inter-related, that is, one aspect of performance (e.g., effectiveness) will not be independent of others (e.g., efficiency). “The reading and interpretation of performance indicators should, therefore, be treated as a system of related measures and never in isolation” (Task Force on the Design of Performance Indicators Derived from the MHSIP Content, 1993, p. 18).

These multi-item measure may be too lengthy for use for those mental health authorities or providers seeking only a few items (e.g., five). Kimmel (1983) reports that “gaming” (distorting data to appear favorably) contributes to the selection process of performance measurement. The research team will need to contend with this possibility. Wholey and Hatry (1992) suggest that gaming could be minimized by the creation of realistic expectations, participatory development of performance indicators, implementation of a balanced system of performance indicators, and using performance indicators for comparisons only with comparable programs and consumers. These conditions are present or have been considered in the design of this project.

Work on Phase Two commenced in June 2002 with a four-day face-to-face meeting of the research team. It is expected that the activities of Phase Two will be conducted from June 2002 through December 2002. The Human Services Research Institute (HSRI) has offered technical assistance with Phase Two activities, assisting in the process of development, refinement and validation.

In Phase Three, the resulting instruments are proposed for undergoing large-scale pilot testing in participating states. Consumers will be surveyed in adequate numbers to conduct psychometric testing. Statistical analysis will likely include: a) computing the descriptive statistics for the scale (means, standard deviations, and item-total correlation’s for each item), b) computing Cronbach’s alpha coefficient for the scale as a whole and for each of its subscales for establishing the scale’s internal consistency, c) computing intra-class correlation coefficients for establishing the scale’s test-retest reliability, and d) factor analysis for the assessment of the factorial structure of the theoretical constructs. In addition, chi-square statistics and ANOVA will be used to examine differences in respondent’s socio-demographic characteristics. If states choose to administer these system-level recovery orientation instruments with other instruments (such as a measure of individual recovery),

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ANOVA or ANCOVA could be used to examine the relationship between level of recovery and the extent to which recovery has been promoted or hindered. We also hope that the extent to which this new instrument correlates with the other efforts currently being advanced in recovery theory and measure development will also be explored.

In terms of normative standards, states have expressed recovery as a goal of public mental health services and clearly the intent is movement in the direction of recovery. The Task Force on the Design of Performance Indicators Derived from the MHSIP Content (1993) advises, “carefully crafted decision rules should be developed in advance and applied uniformly in the application and utilization of performance indicator findings” (p. 42). They specify for example, that high and low performance on any one indicator might be two standard deviations above and below the mean, respectively, and a designation of overall high or low performance is high or low results in at least “X” number of indicators (never just one). In Phase Three, the research team will explore with State Mental Health Agencies the development and adoption of such standards, possibly in the form of a toolkit. The team does recommend that a plan be developed for dissemination of the instrument, the results of Phase Three pilot testing, and the corresponding toolkit (if developed).

## **Conclusion**

Recovery is providing a new vision for the mental health system, a new way of approaching the challenge of psychiatric disability. Our understanding of the process of recovery is in its infancy. We must learn much more in order to transform our current policies and practice, or risk having recovery become the latest buzzword that merely reframes but does not alter past practice.

The *Mental Health Recovery: What Helps and What Hinders?* project research was conducted through the combined efforts of many organizations, mental health authorities, an expert panel made up primarily of researchers who have personally experienced psychiatric disorders; and focus group facilitators, at least half of whom have been, or continue to be, mental health consumers. Through the generous contribution of over one hundred focus group participants—people living recovery and sharing their opinions, experiences and stories—we now know more about what moves people toward recovery and what holds people back.

This study confirms other research on the nature of recovery by showing that the process is very complex. The recovery journey takes people well beyond the bounds of the mental health system. Services and supports offered by the mental health system are only one element of the greater lived experience of recovery. People rely upon many internal and external resources, with the mental health system often playing a part in either promoting or impeding recovery.

The knowledge shared by people in the focus groups is an enormous resource. We need to learn more from the only people who can truly understand recovery—people who are living



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it. We end this report by listening to more of the words from each of the focus group transcripts.

“Implicitly or explicitly getting the message that you will be sick for the rest of your life, you’ll never get well. You’ll have to take meds the rest of your life. Being told that you’ll never work again. The thing that the system has done to hinder and actually damage me the most is tell me I’ll never be well” (AZ, 2247).

“Live your life, not your diagnoses” (CO, 1309).

“Right now I don’t let anything stand in the way of my hope, as my hope is my recovery, and I am only looking up” (CNY, 1398).

“I went to this community mental health center desperate for help only to be told ‘no walk-in’s’—that I must walk out and call them. They do crazy things and act like you’re crazy not to comply” (NYC, 1228).

“We can’t stop here, but there’s hope in watching the system evolve and the changes that are taking place” (OK, 2350).

“My father used to say the dirtiest thing in the world is what comes out of a person’s mouth—derogatory statements. And so instead talk sweet words” (RI, 1730).

“Being a partner in your own therapy and the people who are willing to do it. An active treatment plan with someone who cares” (SC, 215).

“Educating us how to tell our stories to where they will listen and understand. So we know how to present it to them and they won’t be afraid and then they know we do have hope for the future” (TX, 2651).

“Service to other people... is one of the key elements in healing” (UT, 619).

“When people have a choice as to whether or not to access services rather than have those services coerced or forced upon them, then they begin to move into it, they begin to recognize the value of it in their life” (WA, 487).

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## **Appendices**

### **Appendix A: Materials for the Focus Group Facilitator Training**

- ◆ Project Background
- ◆ Sequential Activities of the Facilitator and Focus Group
  - ◆ Focus Group Logistics
  - ◆ Sample Introduction Letter
  - ◆ Sample Focus Group Agenda
  - ◆ Background Information Sheet
- ◆ Suggested Script for Starting the Focus Group
  - ◆ Agenda Question Sets
  - ◆ Suggested Closing Script

### **Appendix B: Consent Procedures and Form for Focus Groups**

- ◆ Procedures
- ◆ Sample Consent to Participate Form

### **Appendix C: Member Check Request**

- ◆ Cover Letter
- ◆ Checklist

### **Appendix D: Cross Site Codebook (Version Two)**



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