

**MENTAL HEALTH RECOVERY: WHAT HELPS AND WHAT HINDERS?
A NATIONAL RESEARCH PROJECT FOR THE DEVELOPMENT OF RECOVERY
FACILITATING SYSTEM PERFORMANCE INDICATORS**

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Phase One Research Debriefing Summary

At the prodding of the mental health consumer/survivor movement, more and more mental health systems and providers are acknowledging the notion of mental health recovery. Such recovery can best be understood through the lived experience of persons with psychiatric disabilities, and through understanding the roles, both positive and negative, that forces and factors play in recovery. But what is mental health recovery? What helps the individual in the process of recovery? What hinders? How do mental health systems and staff help, and how do they hinder? How can these effects be measured? The recent report entitled "*Mental Health Recovery: What Helps and What Hinders? 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,*" represents the first completed phase of a national project designed to address these questions.

Though part of a larger project, the report stands on its own in several respects. First, it explores the many nuances and complexities of recovery, illustrating these by quoting extensively from the study participants. The result is a profound and compelling narrative of the recovery experience, told in the many voices of a diverse cross-section of service users. More concretely, it offers to anyone engaged in the formal mental health system—line staff, administrator, policy maker or service user—a wealth of knowledge about what is necessary for mental health services to be truly responsive to the needs of persons with psychiatric disabilities.

Background of the Recovery Project

There is increasing convergence of defining mental health recovery as the ongoing, interactional process/personal journey and outcome of restoring a positive sense of self and meaningful sense of belonging while actively self-managing psychiatric disorder and rebuilding a life within the community. Definitions of recovery generally identify both internal (self) and external (environmental/social) factors, and the dynamic interplay between them. Hope, empowerment, self-management and social relationships are prominent themes. As the concept of mental health recovery gains recognition, service users and researchers (including service user-researchers) have begun to explore ways to measure an individual's progress in recovery as an outcome. *The Mental Health Recovery: What Helps and What Hinders Project* represents the next step of measuring the degree to which mental health systems, services and staff positively and negatively affect the individual's progress.

The What Helps and What Hinders Recovery Project originated as a collaboration by several participating states that had been independently exploring the idea of recovery-related systems performance measures. Mental health planners and administrators from these states formed a workgroup, to which they added service users and researchers (including service user-researchers) experienced and knowledgeable in the recovery field. The group recognized a need for additional knowledge about consumer/survivor perceptions of what helps and hinders recovery, beyond that available from the literature and the expertise available within the group. Accordingly they formed the five member research team (the majority of whom identified as consumers/survivors), who designed and launched the national project.

The materials herein do not necessarily reflect the positions or policies of any of the project sponsors and state research partners.

The specific aims of the project are to: (a) increase knowledge about what facilitates or hinders recovery from psychiatric disabilities, (b) devise a core set of systems-level indicators that measure critical elements and processes of a recovery-facilitating environment, and (c) integrate items that assess recovery-orientation into national and state efforts for generating comparable data across state and local mental health systems and encourage the evolution of recovery-oriented systems. A group of federal, academic and private organizations are sponsoring the project and ten state mental health authorities (SMHAs) are collaborating in carrying it out.

The work of the project is designed to evolve through three phases. Phase One used a modified grounded theory approach to capture the phenomenon of recovery and the ways in which the social environment, including the mental health system, impact upon the process. Phase One has been completed, and this paper is centered in its results, in particular, findings are highlighted in regards to formal service systems of care and treatment. Phase Two creates and refines 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, these recovery performance indicators will undergo large-scale pilot testing in participating states.

That recovery is a deeply personal journey was reflected in the richness, nuance and personal stories contained in the transcripts that resulted from the 10 structured focus groups with 115 service users conducted during Phase One. Though the data reduction process meant loss of such uniquely personal detail, it did reveal the many commonalities in people's recovery experiences and opinions. Recovery can be viewed by as process and a product of complex, linked and dynamic interaction among characteristics of the individual (the self/ holism, hope and a 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 (choice/ empowerment, independence/ interdependence).

Phase One Methodology Summary

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 was framed as exploratory, phenomenological research using principles of grounded theory (Glaser & Strauss, 1967). 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. This perspective views human behavior as contextual and a function of the dynamic transaction between the person and the social environment (Germain, 1991).

The project used a structured focus group approach to capture consumer/survivor experiences and understandings. Implementing the Phase One common protocol, nine SMHA's recruited a total of 115 service users to participate in 10 structured focus groups. The SMHAs employed a purposive sampling strategy to attain a cross-section of consumers/survivors representing diverse geographical settings, patterns of service utilization, education levels, demographic characteristics, stages of recovery, and involvement in the service user movement. Each state followed policies and procedures within their respective state for research and evaluation activities and administering informed consent.

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.

The majority of the participants were female (at least 58%). The mean age of participants was 47; the range 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. Most all participants identified English as the language they mostly speak 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 as 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 have 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 live with their minor children, 4 live with their parents, 2 live with their adult children, and 1 lives with a sibling. Nine participants reported living with a roommate, 1 reported being homeless, and 2 reported living with pets.

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 times, the average being 10, the median being 6 and the range being 1 to 200. At least 75% of the participants reported having been 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. The more commonly listed diagnoses included bipolar/manic depressive disorder (42), depression (41), schizophrenia (15), posttraumatic stress disorder (14), schizoaffective disorder (13), anxiety (8), borderline disorder (7), and obsessive-compulsive disorder (6). Other diagnoses 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).

Data Collection and Analysis

Trained focus group co-facilitators, one of whom publicly identified as a service user, followed the common protocol and presented participants with standardized, open-ended question sets about what helped and hindered in five hypothesized domains of recovery. One domain, for example, was "resources/basic needs," and the questions were "What resources are important for you to have control of your life?", "What helps you get these resources?" and "What gets in the way of getting these resources?" Similar questions addressed the other four domains of choice, independence, connectiveness (relationships), and hope. To capture the entire range of factors that help and hinder recovery in each of these five domains, the two final question sets about the service system were held until the end.

Raw data included verbatim transcripts of focus groups, written comments provided by participants, and written facilitator notes that primarily concerned the group process. Using structured content analysis, each member of the research team coded one or more of the focus group transcripts and accompanying raw data. Coders notated commonalities, disagreement and gaps within the data, and inductively created an evolving set of critical concepts. Coders then produced a preliminary report for each transcript that incorporated the focus group question sets and themes for that transcript.

More specifically, 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.

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 coding results made sense to them, and that they accurately reflect the discussion in the focus group. 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 participated. A "confirmability index" was calculated on the responses to determine the

proportion of agreement that the coding captured the original content for each question set. The results yielded a confirmability index of 99.47%.

The research team met to thematically compile the coding results across all of the focus groups, first according to the focus group question sets and second according to emergent critical concepts. The research team used a process of codebook development, cross coding and recoding to develop a single set of findings across all of the groups. A final manageable and comprehensive set of 10 domains (e.g., meaningful activities, peer support) emerged from the data analysis, with reoccurring themes (e.g., education and knowledge, stigma and discrimination) cutting across several of these domains.

Findings

That recovery is a deeply personal journey was reflected in the richness, nuance and personal stories contained in the transcripts. The research team, however, had to reduce 1,000 pages of transcript data to a manageable and comprehensive set of domains/themes. Thus, some of the uniquely personal detail was lost. This data reduction process, however, revealed the many commonalities in people's recovery experiences and opinions.

An ecologically based conceptual paradigm for organizing and interpreting the phenomenon of mental health recovery emerges from the study findings. Recovery is facilitated or impeded through the dynamic interplay of many forces that are complex, synergistic and linked. Recovery is a product of dynamic interaction among characteristics of the individual (the self, holism, 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).

The American Dream

Within this ecological context, basic material needs require attention - a livable income, safe and decent housing, health care, transportation, a means of communication (e.g., telephone) - move people towards 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 membership in community 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. But participants reported that they much more often experienced 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 community membership dimensions to recovery, the research team was struck by how generic and universal the responses were to what might be expected from almost any group of American adults, a compelling belief in the "American Dream" of economic opportunity, self-sufficiency, liberty and the pursuit of happiness.

Personhood

The report's findings support "personhood" 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. Dreams demeaned, 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). Access to relevant, accurate information becomes critical, as participants want to understand what they are experiencing, they want to be educated and actively participate in making important choices. It is also important to note that some of the 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, the research team was 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, in the media and in the broader community can move recovery forward.

Empowerment and Self-Help

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. The findings document the crucial role that choice plays in empowerment. Having information on, access to and a range of meaningful and useful choices and options fosters recovery. Participants are empowered when they make the choices regarding where they live, 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."

For such empowerment to occur, however, meaningful options must exist and people must have training and support in making choices, and the freedom to take risks and fail. But too often quality of life choices seemed outside the realistic reach of many participants. Options are limited, lousy or nonexistent. Participants recounted service providers, professionals, family members and communities that responded through the use of coercion, control, restricted access or involvement, discrimination and stigmatization.

Independence, that is, not being subject to the control of others and not requiring or relying on others, 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 linkage of people to people. Seeking independence and interdependence are not mutually exclusive.

Another critical dimension of recovery is consumer/survivor self-help, consumer operated services, consumer recovery role models, and referent power opportunities within the consumer/survivor movement. 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 "experience 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 a lack of transportation, and controlling and mistrustful professionals hinder peer support efforts.

Formal Service Systems

The formal service system, and the professionals and staff employed within it constitute other dimensions that impacts recovery. The research team clearly identified that progress toward recovery can be supported through the formal system. There was, however, within the data much more "hindering" content regarding formal systems than any other domain. Many of these 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 interests of patients. It is critical to acknowledge that the formal system often hinders recovery, and at the core of such hindering forces is the operationalization of societal's response to mental illness, that of shame and hopelessness and the need to assert social control over the unknown and uncomfortable.

Systems currently lack a culture and 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 system concentrate services on medication and medication management, but this alone is too limited a 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-orientated 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. Crisis-oriented systems do not support recovery and well-being, they only respond to deterioration. In addition, many systems have poor crisis and emergency services; some rely on poorly trained and poorly run emergency services in general hospitals.

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. Learned helplessness may result when system encourages dependency. Social entitlements can both reward and retard dependency. If people complain about aspects of the system, there can 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, 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. 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. The system is often focused upon

system self-preservation rather than being consumer focused/consumer driven. People are often socially segregated in mental health programs and stay inside an insular world.

Several structural characteristics of the 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. Funding cuts jeopardize assistance, and financing can support the needs of the system rather than the needs of the consumer. Some people feel they are viewed as source of billing or as a commodity that generates revenues, rather than as unique individuals with unique needs and personal freedoms. 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.

There is poor oversight of programs and systems in some areas, and a critical lack of quality control of services. Records and treatment plans are often not shared with consumers, and some records contain faulty information. This lack of confidentiality hinders recovery. Some participants described substandard service/poor quality of care in the formal system. Substandard services can be offered at the expense of other desired services. 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. 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.

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. 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. 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. There is a lack of timely access to services and care. In some mental health systems and programs 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, or 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 absence of individual service plan hinder recovery. Systems lack the needed range of program/ treatment options e.g. psychotherapy, case management, psychosocial rehab, many others. There is lack of funding for supportive employment and lack of emphasis on higher-level employment. 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. 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.

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 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. 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. 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. 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 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.

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 the 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 fails to incorporate trauma knowledge in existing explanations of, and responses to, mental illness. Pivotal in creating a trauma sensitive and healing 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 - the need for positive helping relationships based on partnership - a “therapeutic alliance.” They want to have people care for them and listen to them and empower them. Respect becomes critical. 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 a doctor, therapist or case manager were strong concerns. People desire complete and accurate information on all possible interventions and supports (particularly on the potential benefits and side effects of medication) and the collaborative development of individual treatment plans. Most people sought to be in charge of their treatment or recovery plans 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. The whole focus of the helping relationship should have this value at its core – the actualization of the individual through self-determination and choice.

Conclusion

The research team does identify 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. Finally, the focus group methodology limits identification of consensus as well as the relative importance of the themes or domains.

The work of Phase One of this project, however, 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 and providers 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) and targeted to many audiences.
- Hope and empowerment are critical and their relationship to recovery warrant 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.
- Adequate resources are needed to fund and support consumer voice and consumer leadership development.

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. A recovery-enhancing system is person-oriented, and respects people's lived experience and expertise. It promotes choice-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.

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. The research team is now fully engaged in Phase Two of the project, creating prototype systems-level performance indicators, derived from the Phase One results, which will assess important elements and processes within mental health systems and providers that facilitate or hold back recovery. In Phase Three, these recovery performance indicators will be pilot tested in participating states. As it did throughout Phase One, this project continues to role model the successful incorporation of significant service user involvement at every stage. Taken as a whole, this project is an invaluable step in the evolution of understanding and advancement of mental health recovery.

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