

Recovery Paradigm Project

DEEPENING THE MENTAL HEALTH RECOVERY PARADIGM, DEFINING IMPLICATIONS FOR PRACTICE

A REPORT OF THE RECOVERY PARADIGM PROJECT

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Many people contributed to the work of the Project. Karen Suddath, Director of the Mental Health Services for the State of Kansas, Charlie Rapp, Associate Dean of KUSSW, and Anne Mathews-Younes, Branch Chief of the Special Programs Development Branch within CMHS provided funding and systems-level leadership for the project. Priscilla Ridgway of KU coordinated the project and researched and developed the recovery paradigm. Kara Mattes, a MSW student at KU helped identify and gather recovery materials. The work to identify important dimensions of recovery was strengthened through discussions with Diane McDiarmid, Charlie Rapp, Liz Gowdy, Linda Carlson and Linda Zebley of KU, and expert panel participants. Debbie McCord, of KU, and ENCORE, Inc., a contract agency for SAMHSA, worked out logistics for the project meeting. Wanda Buck, administrative assistant, worked tirelessly on many mailings and materials development. Staff of the KU Alumni Center also helped the meeting run smoothly.


A national panel of experts on recovery did the major work of deepening paradigm knowledge and defining implications for practice. This panel included:


-  Andrea Blanch, Ph.D., former Associate Commissioner for Mental Health in New York and Maine, has conducted recovery research, held forums on recovery and supported progressive systems-level change. In addition Blanch has undertaken broad-based work in the area of community support services. She provides consultation to mental health policy and research organizations.
-  Sally Clay is a mental health consumer advocate and writer. Clay has directed peer self-help programs in Maine and New York. She is currently working on an evaluation team assessing the impact of a large consumer-run agency in Florida, as part of a multi-site study of peer self-help. Clay also provides consultation to mental health agencies and the courts.
-  Kathryn Cohan is a former consumer/provider of mental health services and the founder of a cyberspace community for women writers who have experienced psychiatric disorder. She is currently working on a project to reduce stigma for the National Alliance for the Mentally Ill from her home base in Rhode Island.
-  Mary Ellen Copeland, MA, MS is a well-known trainer and author of self-help books including The Depression Workbook: A Guide to Living with Depression and Manic Depression. Copeland lives in Vermont.
-  Patricia Deegan, Ph.D. has published and spoken widely on the topic of recovery for over a decade. Deegan co-founded the National Empowerment Center, where she is affiliated. Deegan works to increase recovery paradigm knowledge, bridge the mental health consumer and disability rights movements and develop hands-on recovery tools.
-  Zahirah Duvall is a consumer advocate and executive director of a consumer drop-in center in Portland, Maine. Her program is one site in a national evaluation of peer-run programs.
-  Courtenay Harding, Ph.D. is an internationally known researcher who has produced a

wealth of knowledge on the course and outcome of mental disorders, recovery and best practices. Harding is an Associate Professor, School of Medicine, University of Colorado, Denver, co-principal investigator of a multi-site study of schizophrenia, and Director of the Mental Health for the Western Interstate Commission on Higher Education (WICHE), Boulder.

 Dori Hutchinson, Sc.D. is affiliated with the Center for Psychiatric Rehabilitation and Sargent College of Allied Health at Boston University, where her work has centered on areas of supported education, recovery and wellness. She will direct a new Recovery Center being developed at BU.

 Edward Knight, Ph.D. directs the Consumer Empowerment Project in Albany, New York, a statewide consumer-run organization that builds consumer leadership, develops self-help groups, and conducts public awareness campaigns. Dr. Knight also consults with a major managed care organization, and he and his staff consult with several states.

 Jay Mahler has a long history as an activist in the mental health consumer movement. Mahler was a co-founder and director of the California Association of Mental Health Clients. Currently he is employed by the Department of Mental Health in Contra Costa County California where he is bringing together consumers, family members, and practitioners to develop recovery-oriented knowledge, training, programs and systems.

 Patrick Sullivan, Ph.D. former Commissioner of Mental Health for the State of Indiana, is Professor of Social Welfare at the Indiana University School of Social Welfare. Sullivan has conducted research on strengths model social work practice and has conducted mixed-method quantitative/qualitative research on recovery among people with prolonged psychiatric disability.

These individuals contributed their time, ideas, expertise, hearts and humanity to the project, as did Stacy Tupper, from Contra Costa County (CA) DMH, who attended the meeting, assisting and writing with Jay Mahler. Cherie Bledsoe-Boykin, the director of a peer drop-in center in Wyandotte County Kansas lent her experience to the discussion at the meeting. Nancy Davis, Ed.D., a Public Health Advisor for SAMHSA, participated in the meeting and shared her knowledge of resiliency. Ed Andries attended and provided support to May Ellen Copeland. Cheryl Gagne, from the Center for Psychiatric Rehabilitation could not attend but co-authored a paper on wellness with Dr. Hutchinson. Charlie Rapp, Liz Gowdy, Linda Zebley prepared notes of the meeting. Dr. Harding also made extensive notes that were helpful in preparing this report.

A group of thirty-five people from throughout Kansas, including consumers, providers, and government officials attended the Recovery Paradigm Project meeting as observers. Most participated in a follow-up breakfast where they discussed and integrated what they learned and suggested follow-up activities. A brief summary of that meeting is included in this report.

Introduction

Three decades ago many people were institutionalized as back ward mental patients. Two decades ago concern for deinstitutionalized ‘chronic patients’ was just beginning to give way





to a Community Support System perspective. A decade ago systems were busy designing a continuum of care and psychosocial setting for recipients. Programs supporting people with serious and prolonged disabilities to live, learn and work in the open community were considered innovative. 'Recovery' was a new term.

Today recovery is a major buzzword in the mental health field. Mental health leaders want their programs and systems to be recovery-oriented. Many journal articles, research projects, and conference presentations over the last 10 years have focused on this topic. Despite the general push toward recovery, the concept has remained somewhat illusive. Sometimes the term seems to be mere rhetoric; when used shallowly it carries little meaning. Sometimes recovery seems too complex to grasp. The field lacks a firm understanding of implications and applications of recovery concepts. Just what is recovery? What does recovery mean to people, programs and systems? Is recovery simply a faddish re-naming of things that are already happening or does recovery require the mental health field to retool from the ground up?

Mental health systems are beginning to focus seriously on assisting people with psychiatric disability to recover and move on with their lives. Knowledge and experience concerning recovery is growing in pockets throughout the nation and in other countries, but in-depth information is hard to find.

After more than a decade of interest, it is time to take another look at the concept, to examine and integrate what we know, and to build a stronger and deeper understanding of the emerging paradigm. This project is one of several efforts to understand recovery occurring across the country.

The Recovery Paradigm Project was intended to accomplish several goals:

-  to identify the most crucial elements of recovery,
-  to build a coherent parsimonious conceptual model of recovery,
-  to identify a panel of national experts on recovery who could take one part of the recovery puzzle and build in-depth understanding of that element and share their expertise with one another; and finally,
-  to more clearly define recovery-oriented practice.

To accomplish this project, written and multi-media materials on recovery were gathered. This data base was not exhaustive, but it did contain extensive published and unpublished materials. The materials included first person accounts of recovery, reports of qualitative and quantitative recovery research from the US, Sweden and Australia, systems-level policy planning documents from several states, videotapes, newsletters and the contents of several internet sites.

An analytic review of these materials was conducted to identify critical dimensions of recovery. Emphasis was placed on defining recovery from the viewpoint of mental health consumers. Later steps will identify general principles for a recovery-oriented system and best practice elements. The first stage of the project built upon earlier recovery training designed and conducted by Ridgway and Diane McDiarmid of KU and qualitative research on important themes found in recovery narratives undertaken by Ridgway.

Initial findings of the analytic review were discussed within the mental health research group at KU and with several experts participating in the project. The mental health recovery paradigm was also presented in workshops in San Francisco and Minneapolis to gain feedback. Steve Onkin of the University of Texas, Austin and Peter Ashenden of the Consumer Empowerment Project, Albany, New York collaborated with Ridgway on these workshops.

The Emerging Mental Health Recovery Paradigm

While recovery from psychiatric disability is clearly very complex, patterns do emerge upon carefully examination of the phenomenon. These patterns seem to hold up across data sources (similar themes are found in first person accounts, qualitative and quantitative research, and conceptual writing). They seem to bridge treatment eras (descriptions of similar processes are found in 18th century and contemporary recovery narratives) and cross geographic boundaries (contemporary research on recovery from Sweden and Australia, both western cultures, reveals similar patterns). When people in recovery and professionals engaged in recovery research or practice review these dimensions they confirm their importance and are unable to identify important elements that are lacking.

The final set of elements of the emerging mental health recovery paradigm includes three major domains and nine elements. The first domain concerns reclaiming a positive sense of self in relation to the psychiatric disability. The second domain concerns the move to an active mode of contending with disorder and disability and the pursuit of health. The third domain concerns moving on, the process of reclaiming meaningful roles and a life beyond being a consumer in a formal helping system. Characteristics of the overall journey of recovery were also identified.

This conceptual model describes recovery as a series of journeys that are inter-linked rather than as a set of static outcomes. While words on paper flow in sequence, the mental health recovery paradigm is not linear. Recovery is a set of dynamic, complex transactional processes, in which the environment, the person, formal and informal systems, opportunities and interpersonal relationships, chance and transpersonal dimensions all seem to play important roles.

This general conceptual model is not intended to be prescriptive, because people do not all begin the recovery journey at the same place, they follow different paths and their lives take different turns, everyone does not end up in the same place. Any human process is too complex and too mysterious to be captured in a few words. To really understand recovery we have to move beyond words on paper and travel together on what Pat Deegan calls ‘a journey of the heart.’

THE EMERGING MENTAL HEALTH RECOVERY PARADIGM

Recovery is Reclaiming a Positive Sense of Self in Spite of the Challenge of Psychiatric Disability

The Journey from Resignation to Hopefulness & Realistic Optimism

The Journey from Alienation to Meaning & Purpose

The Journey from Mental Patient to Personal Identity Beyond Disorder Including Battling External and Internalized Stigma and Reclaiming Self-Respect

Recovery is Actively Self-Managing One's Life & Mental Health Disorder

The Journey from Passive Adjustment to Active Consumerism

- Moving Beyond Denial--Creating a Framework of Understanding & Accepting the Challenge to Recover
- Moving Beyond Total Reliance on Expert Knowledge to Self-Directed Recovery
- Learning from Others Facing the Challenge of Recovery in Mutual Self-Help
- Partnering with Professionals
- Increasing Voice, Consumer Involvement to Active

The Journey from Stress-Vulnerability to Active Self-Management and Hardiness

- Identifying Personal Stressors and Self-Managing Daily Hassles and Stressful Life Events
- Developing Individualized Skills and Means to Self-Control or Self-Manage Symptoms

Journey from Self-Neglect to the Development of a Positive Lifestyle, Self-Care and Wellness

Reclaiming a Life Beyond the System

From Life Spent in Program Environments to a Life Space in the Community

- The Journey from Rootlessness to a Sense of Home
- From Closed Programs to Empowering Niches and Natural Community Settings


The Journey from Withdrawal and Inertia to Active Participation in Meaningful Activities


- The Creative Process
- Learning
- Employment (including the role of Consumer-Provider)


The Journey from Social Isolation to Relationship & Sense of Community

- Intimacy, Parenting, and Family (including Ethnic and Gender Preference Diversity)
- Chosen Supportive Relationships
- Involvement and Sense of Community


Recovery is Re-claiming a Positive Sense of Self In Spite of the Challenge of Psychiatric Disability


 **The Journey from Resignation to Hopefulness & Realistic Optimism** People with psychiatric disabilities often have a sense of hopelessness and become profoundly pessimistic about their life chances. In recovery people become more hopeful, they come to believe recovery is possible and they come to know that their own actions can influence their life experience in positive ways.


 **The Journey from Alienation to Meaning & Purpose** Psychiatric problems disrupt the life course. A profound sense of alienation and meaninglessness often results from the experience of prolonged psychiatric disability. As people recover, they find meaning in their experience and develop a renewed sense of purpose and direction. Their attention turns to new goals and a sense of purpose is rekindled in their lives. Some people make an active commitment to assist others in recovery or advocate for needed changes in programs and systems, and this work makes life fulfilling. Faith and spirituality are often important sources of direction, meaning and purpose on the journey of recovery.

 **The Journey from Mental Patient to Personal Identity Beyond Disorder Including Battling External & Internalized Stigma and Reclaiming Self-Respect** The role of service recipient can become a full time undertaking. As other roles and interests fall away people come to identify primarily with their psychiatric label; people come to see themselves as ‘schizophrenics’ or ‘bipolars.’ Social stigma creates a sense of shame. In recovery people come to honor themselves, their struggles and their own unique identities, they reclaim interests, and discover and build on their strengths. They battle external and internalized stigma and reclaim a sense of self-respect.


Recovery is Actively Self-Managing One’s Life & Mental Health

 **The Journey From Passive Adjustment to Active Consumerism** In recovery people begin to reduce the use of the protective mechanism of denial. They develop a framework for understanding their experience that removes the disability from the core of their being. They come to view their life situation and disability as something that they can contend with. They accept the challenge to recover and begin to work on their own behalf. People move beyond total reliance on expert knowledge and begin to self-direct their own recovery. They learn from others facing the challenge of recovery in mutual self-help and partner with professionals. People reclaim a sense of agency and voice and begin speaking and acting for themselves, and may join with others to work to change programs and systems.


 **The Journey from Stress-Vulnerability to Active Self-Management and Stress Hardiness** Prior to recovery people tend to avoid activities and relationships that are stressful or they may contend with stress in ways that hold them back from growth in the long run. Some succumb to stress associated with poverty, stigma, or homelessness and find it difficult to achieve equilibrium. In recovery people actively engage in life. They find ways to contend with stress. They learn to identify sources of stress and discover ways to contend with daily hassles and stressful life events. People develop individualized supports, skills and means to self-control or self-manage symptoms and extreme states. They begin to take on more challenges, and over time, they become much more hardy in the face of stress.


 **Journey from Neglect to the Development of a Positive Lifestyle, Self-Care and Wellness** Prior to recovery, people often ignore their bodies or they may engage in behaviors that increase the risk of illness or jeopardize their well-being. In recovery people often organize a positive life style for themselves that includes attending to their own health and wellness.

Recovery is Reclaiming Roles and a Life Beyond the Mental Health System







 **From a Life Spent in Program Environments to Life Space in the Community** Prior to recovery people often feel that they do not belong anywhere. They spend their days in enclosed socially segregated program environments. As people recover they begin to

create a life space for themselves in the community. They work to achieve a sense of home, find places to practice their spirituality, work and learn. They begin enjoying themselves in community settings. While they may spend time in empowering niches created to support recovery they spend the majority of their time in typical community settings.

 **The Journey from Withdrawal and Inertia to Active Participation in Meaningful Activities** Prior to recovery people often withdraw into a state of inertia. In recovery people begin to become more active and participate in meaningful activities. Their well being is enhanced through creative pursuits, they further their education or otherwise learn new things. Many begin working, and some find they want to give back to others in the role of consumer-provider.

 **The Journey From Social Isolation to Relationship & Sense of Community** People often withdraw from others prior to recovery or feel rejected by others. The journey of recovery is not solitary; it is a social process. People in recovery move beyond one way relationships in which they receive services or support toward more balanced give and take relationships. They end poor relationships and establish supportive relationships and a circle of friends. They form or improve intimate relationships, some become parents, and some work to improve relationships with their family. Social processes of recovery reflect diversity, because some groups have very different responses when a person has a psychiatric disability. In recovery people work to contribute to others and achieve a sense of community.

Recovery is a Challenging Journey

-  Recovery is a unique process for each person.
-  Recovery is triggered in many ways—including the spark from "turn-around people" who recognize one's worth or the fuel of anger at the denial of one's potential.
-  Recovery is a nonlinear process, with spirals and difficult passages.
-  Recovery requires perseverance, endurance, strong intent, self-will, and self-awareness.
-  Recovery is not "cure," it is an active on-going process of self-directed healing and transformation, that often, but not always, involves formal treatment and rehabilitation.
-  Recovery markers or outcomes can be defined and substantial or full recovery are achieved by many. But, individual's path and goals vary based on personality, interest and motivation, choices, ethnicity or culture, life experiences and stage of life, access to resources, local context, strengths and assets, and the life challenges faced.

The Paradigm Project Meeting

A panel of national experts was recruited to explore and deepen knowledge on crucial dimensions of the emerging recovery paradigm. Each agreed to write a draft paper on one element and to attend a two-day meeting to discuss their ideas. The meeting was held in

Lawrence, Kansas on the June 2nd and 3rd, 1999. The papers prepared for the meeting will be edited and published.

KU Associate Dean Charlie Rapp and Karen Suddath Director of the Mental Health Division for Kansas made introductory remarks. Rapp indicated that the field's response to recovery could be likened to the early response to the strengths model of practice developed by Ronna Chamberlain, Rapp, and colleagues at KU. When they began strengths model training half of those attending felt they already applied the approach and half felt it was absolutely impossible to implement. The Recovery Project was intended to increase clarity concerning critical elements and processes of recovery, and to begin to define applications.

Dr. Nancy Davis discussed the Center for Mental Health Services' interest in the concept of resilience and the related concept of recovery. Dr. Davis' recent work integrates knowledge and research on resiliency across the life span, and defines elements of model programs that promote resiliency. Resiliency is the ability people have to successfully contend with adversity, function adequately and achieve a positive future. Rather than viewing people 'at risk' we need to see them equally as 'at promise.' Even the brain is now viewed as having much more plasticity and changes with learning.

Dr. Davis described work being undertaken at the federal level to fund resiliency research and innovative programs in areas such as avoidance of youth violence. Davis described characteristics often found in resilient individuals—hope, the ability to recruit and maintain people to provide assistance, friendship, self-awareness, the ability to problem-solve and carry out plans of action, mastery, creativity, a sense of humor, active participation in life on behalf of others, and spirituality or faith.

Ridgway presented the recovery paradigm model described above. She stressed that even though a general model of recovery was being offered, each person's recovery process is unique. No cookbook or lockstep process of recovery is possible. Each individual must enter into a personal journey of recovery that requires self-effort, perseverance and courage. People have different turnaround points, different experiences and end up achieving different things.

Recovery may be thought of as evidence of resilience in people facing severe adversities associated with psychiatric disability. Ridgway described resilience as:

- an innate human capacity,
- the ability to successfully contend with and overcome personal vulnerabilities and external adversities,
- a complex set of self-righting capacities that exist within stressful life circumstances, and
- the capacity for positive growth and transformation across the life span despite difficult challenges.

She described resilience as 'ecological' because the ability to access one's own capacity for resilience is in part dependent on contextual factors and the social environment.

Environments and programs can facilitate resilience and recovery or they can block these natural processes. She described the characteristics of resiliency-facilitating environments adapted from a review of the literature.

Qualities of Resiliency Facilitating Environments

- Challenging environments that promote participation, learning and striving
- Hopeful environments that promote positive expectations, that inspire and encourage
- Resource-rich environments that meet basic needs, provide choices, opportunities and needed supports
- Caring environments that are respectful and compassionate
- Environments provide opportunities for meaningful participation and significant contribution
- Environments that help people feel powerful
- Environments that connect people to one another in meaningful ways

Unfortunately, mental health settings often lack such characteristics and hold people back from recovery and from experiencing their own potential. If we want people to recover, we must be provide settings with characteristics that are known to promote natural self-righting processes.

Dr. Courtenay Harding discussed the empirical evidence of recovery. She presented major findings from many longitudinal studies of people with psychiatric disabilities conducted around the world. Research findings consistently demonstrate many, even most people recover significantly from prolonged psychiatric disability over time.

Given strong evidence-based research, why do many mental health professionals continue to provide consumers and families with negative messages about their potential for recovery? Harding described how inaccurate historical assumptions are repeated in contemporary clinical education. Such messages are embedded in the process of socializing clinicians into a chronicity paradigm. Lack of attention to recovery also occurs due to truncated diagnostic assessments, inadequate care (e.g. a 15 minute med check once a month now take the place of a therapeutic relationship), researcher bias and clinician illusion, and other factors.

Dr. Harding described psychiatric disorder as a dynamic process that interfaces with human development trajectories, gender, changes in treatment and social systems, and characteristics of program environments. Sometimes recovery just takes time, but turn-around often begins within several years of onset of major disorders.

She expressed frustration with the fact that we have known what to do to assist people to recover for more than forty years. Based on evidence from early rehabilitation research, programs that have certain characteristics pay off with lots of recovery across many domains. These features include:

- meeting basic needs,
- emphasis on self-sufficiency,
- support for positive role functioning,
- provision of practical assistance based on peoples' expressed needs,
- the nurture of long term therapeutic alliances with skilled clinicians, and
- having consumers drive program innovation and their own rehabilitation process

Such programming has been shown to help even those with prolonged and severe disorders (e.g. 'back ward' 'low functioning' institutionalized patients who did not respond to drugs) to recover. Dr. Harding's research indicates that life-long use of psychiatric medications does not appear to be required for recovery. Some people who use medications consistently do not

recover while others do, some people who use meds at some points in time recover, and many who take no meds also recover.

These findings lead to a discussion of meds in general. Some members of the expert panel stated emphatically that they will take psychiatric medication every day for the rest of their lives in order to avoid the potential for disruptive return to psychosis, and would never attempt to talk any other person off medication. Others on the panel view heavy medication as a major impediment to recovery. Some take no meds even when temporarily experiencing extreme mental states, others essentially take low dose meds and control their own dosage based on their self-assessed needs.

Later in the meeting meds were described as a tool for recovery, but only one among a number of tools to control symptoms. If other tools were made available there would be less reliance on drugs, especially rampant polypharmacy, and less pressure from drug companies that influence programs and clinical practice so profoundly. Systems would also have formal assistance for people to appropriately come off medication that can cause devastating side effects.

Harding pointed out that approaches to mind-body healing that acknowledge the importance of spirituality, understand brain function is malleable, acknowledge that the mind can affect brain and body functioning, and accept the healing function of hope are being integrated in other aspects of the health care system. Ironically, the mental health field has fallen behind.

The group turned their attention to the first domain of recovery: "Recovery is Recapturing a Positive Sense of Self in Spite of the Challenge of Psychiatric Disability."

Dr. Deegan discussed the first element: "The Journey from Resignation to Hope." Her paper used the metaphor of the seasons to explore recovery processes and the importance of hope.

Deegan asked the group to consider what people are recovering from. She challenged people to move beyond the idea of biological determinism to look at larger issues. If there were no external social conditions such as poverty, racism, alcoholism, childhood abuse, homophobia, just how much mental illness would there really be? She encouraged people to view recovery not simply as a personal process but as a larger human struggle for liberation, social justice and humanity. Bledsoe-Boykin described the difficulty of attaining or maintaining hope or a sense that one may have a positive future while living in a community severely impacted by poverty, crime and racism. Deegan challenged the group to learn more about how diversity can shape recovery. Some people, cultures and subcultures will experience very different recovery processes, for example, because not every group idealizes individuality, autonomy and self-sufficiency.

Deegan and others discussed the mystery of recovery. There are many unanswered questions, such as why some people get better, why others' suffering worsens, and why people remain in extreme mental states or suffer prolonged disability despite their wish for and work toward healing. Recovery and healing are processes that should be treated with wonder and awe. What if recovery is a matter of grace, an undeserved kindness? What if people sometimes recover in spite of everything rather than because of anything?

While some people seem to return to a former state and reconstitute their former life after psychiatric disability, this seems uncommon. Recovery often does not mean a return to a

former state but real transformation. Some people become greater in this process. While none would wish any other person the experience of prolonged psychiatric disability, most honor the transformation that happened in their own lives through their suffering and struggle.

To achieve recovery we will must critically examine the structures and processes in the mental health system that dehumanize people, such as the intense negative experience of restraint, involuntary treatment and forced medication. These Deegan characterized as 'macro-aggressions' that break the human spirit. Others concurred that it can be more difficult to recover from unnecessary wounding, abuse and trauma within the mental health system than from the psychiatric disorder itself.

Deegan asked people to consider the impact of 'mentalism,' a term first coined in the 1960s as analogous to oppressive processes of racism and sexism. Mentalism sets up internalized images from the culture through embedded social processes, such as media and language, that allow people to hold a host of institutionalized negative attitudes and assumptions and to view someone with a psychiatric label as less than human. Mentalism results in hundreds of 'micro-aggressions' that serve to oppress people with psychiatric labels and strip them of hope. Those who challenge mentalism, whether they are people who are oppressed or those in solidarity with them, are marginalized.

Blanch stated that it is often professionals and systems that need to recover, not mental health consumers. Staff often perpetrate and put up with micro-aggressions and refuse to connect with others as real human beings, while consumers will often challenge such practices or refuse to participate in oppressive programs.

Deegan sees recovery as an active verb and not a noun. Just what processes are occurring within the overall recovery journey? For example, is there a shift in internal self-talk that occurs in recovery? What types of recovery narratives exist that may represent different recovery processes? How does turn-around happen and how is it different for different people? What is the state before active recovery we characterize as inertia—what is that experience about?

The group discussed inertia and meaninglessness. Are we setting up people who are in such a state, and who may remain in such a state for some time, to be seen as less worthy than those who are actively recovering? Are we potentially harming people by devising a recovery paradigm that emphasizes only the movement away from such a state? We must honor people as they experience this part of the human condition.

People often endure a period of deep inertia, alienation, abject meaninglessness or profound lack of vital energy prior to recovery. This was true for almost all the consumers in the meeting. People must be supported during such a period, and held in relationship. But it is very scary to be in the presence of anguish and suffering and maintain an I-Thou presence. At a time when people need the support of others deeply, we often isolate them. Kathryn Cohan warned the group not to suffer 'hardening if the categories.' For years she 'lay fallow' but that time was important in her life. Opportunity arises out of what appears to be a tragedy.

What does that state of inertia really represent? Some people are grieving what they have lost in their life. Some are without hope and feeling helpless to act on their own behalf, they feel the utter lack of possibilities or fear they will crack up again under too much stress. Some people are resting and recuperating because they are exhausted after the firestorm of

psychosis. Some are gathering their energy, or rehearsing or planning their recovery within themselves—they are ‘beginning to get ready to start.’ Some are on heavy drugs that make it nearly impossible to function. Some are watching to see whether they are safe or truly cared for, or they are hiding behind a mask of passivity because recovery is very scary. Some are using passive resistance in situations that are invasive, inane or paternalistic. Sometimes they are stunned and traumatized because of treatment they have received, and may be afraid to open themselves to anything or anyone because of the potential for re-traumatization. They may have suffered at the hands of people in authority who hurt and abused them in the past. Sometimes people are active in their community, but plop themselves in a ‘coke and smoke’ mode in mental health programs. Often boring programs put people into a kind of suspended animation. Sometimes vital energy is completely blocked and a person truly can not even force him or herself to do even a simple activities.

No one can be written off in such a state, because turn-around, awakening, and transformation remain possible. People have recovered from such a state even after thirty years of extreme psychiatric disability. Several participants described what their lives were like when they were in such a state (e.g. rocking, smoking, staring at television or staying in bed for months and years or being the quintessential bizarre, scary homeless person on the street). Now people say to them "recovery may be all right for you, but you aren't sick like my patients, clients, child."

The group discussed how hope may be engendered. Hope often comes in the form of relationships. The rupture of community, social isolation, being set outside the society, being judged negatively because one does not work, being seen as worthless, the experience of loosing everything (relationships, jobs, cars, possessions) repeatedly, the lack of supports available, and grinding poverty make people despair. At points when people feels hopeless, others must hold hope for them. Hope arises in the presence of nurturing, honest, authentic relationships. Positive peer role models are very important, because consumers can see and really understand that others have ‘been there and back.’ When consumers move out of self-absorption, awaken compassion for others and begin helping their peers, hope grows. Where there are positive role models change and hope become contagious.

Authentic relationships between staff and consumers also engender hope. We really know very little about mental illness and staff need to admit their ignorance and powerlessness, accept people's feeling and not meet human feelings with a false façade (what Knight called phony ‘WalMart helloism’), inaccessible language, intellectual abstractions, or a standardized treatment protocol. Inauthentic, paternalistic, and unequal power relationships, artificial professional boundaries, low staffing ratios, pseudo-human exchange of ‘active listening,’ keep people feeling estranged and hopeless. We must be able to say when people walk into programs "We have a tremendous hope for you to recover and have a good life." Healing relationships are two-way, with each person disclosing his or her own humanity, each person learning from the other.

Power imbalances in programs need to be leveled so that people can work together in partnership. People are often labeled as ‘manipulative,’ ‘in denial’ or ‘grandiose’ when they are trying to contend with getting their needs met or protecting themselves from profoundly negative messages. Consumers must play important roles in shaping their treatment plan, agency programs and policy. Knight recommended that there be no more programs in which consumers get to pick the video or choose between macaroni and cheese or hot dogs and staff decide everything else.

The group discussed how important it is for the mental health system not to kill, crush, or rub out peoples' dreams. Programs often actively strip people of hope. Deegan would not tell her psychiatrist her dream of becoming a professional in order to change the mental health system. She knew her goal was unacceptable and would not fit his prediction that she would be disabled for life. Ed Knight and Mary Ellen Copeland had dreams of assisting others to recover through self-help, but were told by mental health professionals that they were experiencing grandiose delusions. One psychiatrist told Knight, in a hush-hush closed-door exchange, not to give up his 'delusions' about self-help because they actually represented his life goals. Dr. Knight has facilitated the formation of several hundred self-help groups and developed extensive self-help materials. Mary Ellen Copeland challenged the idea that people can not actively assist in their own recovery. She researched symptom self-management techniques and wellness with help from Vocational Rehabilitation. Copeland has authored or co-authored several books, one of which has sold over a quarter of a million copies and she now conducts training around the country.

People need to be helped to explore their dreams and goals. People have to take risks to recover and must not be told to avoid acting or living their dreams to avoid stress or symptoms. When people are stabilized, clinicians often actively discourage movement into recovery because they are afraid the stress of forming relationships or working will create a crisis and the return of active disorder. Recovery can be scary, but it is a contagious process. Helping people identify and use their strengths is also very important in this process.

Sally Clay used part of her life story "Me and Them" to illustrate the element of recovery that concerns "The Journey from Alienation to Meaning and Purpose." She discussed her attempts to stop 'mad' thoughts, and the need to accept ones' fears and have support while doing so, rather than suffer the abuse and institutionalization that occurred in her life. She spoke of trying to fit into the role of housewife and the dominant culture, but loosing her marriage and spending many months institutionalized because of manic episodes and subsequent inactive states. She experienced shock treatment that left her with gaps in her memory that broke the continuity in her life story, and took heavy medications that dulled her intellect and emotions.

Clay found renewed meaning in motherhood, acts of nurturing and joyful activities with her child, yet she lost custody based on the stigma of her disorder and the shock treatments she had received. Employment helped her to reclaim meaning, structure her days and build self-esteem. She described the stigma she experienced as a kind of marking of the soul.

Clay's psychotic experiences always contained seeds of deep spirituality—the profound emptiness she experienced while institutionalized had a spiritual quality, and visionary or wisdom experiences were part of her recurrent psychotic episodes. Mental health professionals totally invalidated her experience, continuously discounted them and denied that there could be any positive or spiritual purpose for them. Nevertheless Clay was seduced by some of the qualities of 'madness'. She learned she could evoke wild qualities of mind with alcohol and music.

A turning point, the awakening of compassion for others that occurred in a seemingly small incident at work, had deep implications for her life. She had considered herself a breed apart, but the seeds of compassion helped heal this profound estrangement. Later in her life she learned through spiritual practices to control her mental processes, and no longer suffered psychotic breaks. She was directed by a spiritual teacher to undertake acts of compassion for others, and redoubled her efforts to lead others in self-help. Her madness was her teacher, and

she found other teachers, including other consumers. She discovered her spirituality could have a mundane face, and that compassion for humanity and helping others, through the vehicle of peer support, healed alienation. The fruits of her spiritual learning took time to ripen.

Kathryn Cohan examined the element of the "Journey from Mental Patient to Positive Identity Beyond the Label." In researching her paper she found that there were no models or concepts of human development after the experience of psychiatric disability. It is as though people had arrested development, their lives stopped, they disappeared or their life process was aborted and they entered a kind of limbo. The culture is actively hostile to people with labeled identities. People are viewed as 'useless eaters' or social liabilities. Measured against the yardstick of normalcy they are found lacking. We suffer from the cult of rationality and disallow much of the range of human experience. People with psychiatric labels experience profound shame, stigma and discrimination. These labels warp people into objects.

One can achieve a kind of acceptable status by being 'a good patient' or one may be allowed limited controlled social participation or may perform tasks that are undesirable to others. Yet people awaken out of this state, rally against it or experience a turning point after 'hitting bottom' and go on to experience transformation. Cohan found herself failing at being a good patient, because traditional treatment did not result in remission. She found a little solace in being considered one of the sickest people in her state. She found she could not reject her disorder, but rather had to embrace and befriend it, learn from it, deal with her life and relationships day to day even while experiencing symptoms, and take responsibility for healing her self, with the help of trusted others. She found wisdom can come from attending to ones own suffering.

What can the system do to help people achieve meaning and a positive sense of identity? Knight pointed out that meaning may not be achieved at turnaround, but rather develops as the recovery journey progresses. You have to attain meaning by doing meaningful things. He started out on his recovery journey in a state of alienation and intense meaninglessness, simply by putting one step in front of the other. On the other hand, meaning should be considered as important as other basic needs. Questions of meaning cannot wait until people have attained a certain level on Maslow's hierarchy of needs. Meaning is just as important to a human being as housing or food. The group felt recovery required dropping labels, and contending with phenomena directly, rather than invalidating people's experiences and trying to constantly to reject, counter or bury them. Systems and helpers should always use 'person first' language to acknowledge the disability is not as important as the person's individuality and humanity.

Developing a sense of humor is important when living with mental disorder—Kathryn queried "how about a manic cleaning service or an ad agency that employs schizophrenics to come up with novel ideas?" Spirituality and spiritual practices can keep people from despair and suicide, but Duvall pointed out, we must avoid "forced meditation" in programs just as much as "forced medication." People need roles, niches, and positive places to get better.

Many people are finding that working in mental health is an important part of recovery because they can give back. Reciprocal relationships and self-help provide opportunities for giving and compassion, but people seldom have the opportunity to undertake self-help, and are often actively restrained from sharing with one another.

The Kansas Recovery Breakfast

A number of people attended a breakfast meeting on the day after the Recovery Paradigm Project Meeting. The purpose of the breakfast was to discuss reactions to the recovery experts forum, to gain input about next steps in recovery for Kansas, and to kick off a year-long effort to create a recovery-orientation across the State.

Director of Mental Health Karen Suddath led off the discussion with her own reactions and areas of interest. These included an interest in pursuing the concept of mentalism and how it plays out in local agencies and in state government, as well as how spirit-breaking practices can be identified and changed. We need to examine bigger social problems and their effect on the process of recovery. One person offered that mentalism is not examining our own assumptions.

Suddath was very interested in the whole process of recovery and the idea that people become motivated to recover in their own time. She pointed out we only have active treatment plans, and asked whether we should push people into activity all the time and never give them the opportunity to rest. She asked whether we sufficiently understand and account for the effects and side effects of medications or processes such as ‘woodshedding’ (periods in which people are practicing and getting ready for change); and whether we leave room in all our activity for the mystery of recovery. Do we allow people to “bottom out” or stay in inertia, and how does this fit with the idea of assertive outreach? She questioned the use of forced treatment and wondered if early intervention could be misused and actually act to create labeled identities. What would happen if we used normalizing terms like ‘extreme states’ or dropped all labels?

Several people described the recovery paradigm meeting as profound, eye-opening, even life-altering. Many felt honored to have been included. The group discussed the idea that people can have well-being and illness side by side in their life. It is difficult to judge another’s process. What would happen if staff stopped trying to manage illnesses and began helping people manage their own wellness?

Some people felt the spiritual aspects of the recovery journey were very important and some felt it could be very challenging. In some ways we have to start listening to the other person heart-to-heart instead of having head-to-head discussions. We have to begin to pay attention to the mind, body, and soul. Moving toward more authentic relationships is important but power imbalances cannot simply be wished away. Staff must have good supervision and open discussions when mores are changing.

Kansas lacks a really strong consumer movement, and a recovery orientation emphasizes self-help. Consumers need adequate rewards, more technical assistance and leadership development. More consumers need to serve on the boards of agencies, so that this legal requirement isn’t simply tokenism. Consumer-run organizations need greater resources and more should be established.

The importance of hope and the role consumer providers can play in building hope was emphasized. The work going on to train and hire consumer-providers is very important because it helps people see they can recover and achieve the identity of helper. Even when a

consumer-provider goes through a rough period, other consumers can see the person weather the episode and return to work. Some ethical, legal, licensing and practical issues remain to be resolved. Mahler offered to provide information on resolving ethical issues such as dual relationship, because California has dealt with such issues of hiring consumer providers for nearly ten years. We should speed up the learning curve and learn from others systems who have had consumer-providers for years, to resolve these conflicts as quickly as possible. Some felt issues such as dual relationships are being thrown up as artificial roadblocks by agencies that just do not want to embrace change.

Sometimes programs want to protect people from being hurt, but this stops them from growing. We can not protect people by wrapping them up in cotton. There is the potential in any human relationship (including between staff and consumer) of being hurt, but people can open to relationship, experience joy and pain and grow.

An emphasis needs to be placed on facilitating natural ways for people to get help, rather than putting people in a protective bubble. We need to work on developing natural community supports and *community mental health*. Artificial programs can get in the way of recovery. Some times the ‘cure is worse than the disease.’ We need to look at the environments of programs and how they promote mentalism and socialize people into ‘good patient’ behavior. We may need to change the word consumer because it implies a one way relationship.

Recovery should be seen not as a program but as the need to change our perspective, our world-view and treat the whole person. We need to share this vision because it is more creative and freeing. We need to understand that each person has many gifts, a story and a unique recovery journey and begin to support people in this process.

Kansas needs to build on its strengths and history. We don’t have as many ‘evil empire’ programs to be dismantled. There is new statewide leadership to help put the vision of recovery forward. We need to build toward recovery by investing in consumers, involving families, consumers, the legislature and governors office, CMHC’s, KU and outside people to move the system into a recovery orientation.

Moving the Recovery Paradigm in Kansas Suggested Strategies and Next Steps

The following activities were suggested at the breakfast and in follow-up discussions.

Create a Strong Vision of Recovery

- Inform people of recovery paradigm and conference
- MH Division develop recovery vision statement
- Encourage each Center & CRO to develop its own recovery vision statement that builds on the statewide statement
- Form a state level Recovery Advisory Committee or task force to advise the Director of Mental Health. Include consumers, families, KU & providers to formulate vision paper,

etc.

Build Local Leadership and a Workgroups

- Identify recovery work groups in each area of the state that include consumers, providers, family members, etc.
- Have each work group identify a point person
- Communicate with, provide info & TA to work group leaders (consistent contacts, ideas for discussion points, tasks, resources)
- Quarterly meetings to bring regional group leaders together to brainstorm/ share resources and ideas, to learn from & support each other

Raise Consciousness & Provide Basic Information

- Add recovery content to Making a Difference & DMH newsletters, article of the month
- Compile a basic set of reading on recovery & distribute through local work groups
- Identify & organize basic materials on recovery in a clearinghouse
- Discuss recovery at on-going meetings (CSS directors, State Planning Council, etc.)
- Work groups use dialogues on hope and recovery locally
- Encourage local work group to discuss mentalism/ macro and micro aggressions/ spirit breaking & how to avoid
- Have local groups provide in-service training and activities to area programs

Provide Training in Awareness & Skills of Recovery

- Statewide recovery conference planning committee
- Plan, develop and conduct regional trainings
- Have Kansans receive training for trainers in Copeland WRAP plans

Build a strong cadre of local trainers

- Identify; acquire training materials
- Develop training packets for centers/other programs/CROs/students in practicum sites
- Develop recovery training for professionals (CEU workshops)/ professional training programs

Increase Consumerism

- Hire a consumer affairs officer for the State
- Form a consumer affairs advisory committee
- Development further self-help opportunities in each area
- Increase salaries and funding for CRO's
- Support on-going consumers-as-providers efforts
- Work to resolve consumer as provider issues

Identify experts and gather info from other states

- Highlight consumers in Making a Difference etc.
- State Government (DMH) staff advocate with Professional Boards
- Put info on hiring, supervision and resolution of issues into the hands of each center and their personnel people
- Build knowledge on ADA and accommodations
- Set aside funds to send consumers to national conferences
- Make sure consumers are involved in all steps
- Increase consumer involvement on boards

- Create a consumer leadership academy
- Conduct TA for CROs on issues such as board development, management, team building

Develop Model Recovery Programming

- Build the capacity of selected programs through training and targeted resources, to build and showcase "model recovery programming"
- Work to further elaborate implications of recovery for services and systems
- Develop innovative programming

- Research, design and test the effectiveness of advance directives
- Over time evaluate model programs and materials (evaluation research)
- Package and disseminate work throughout the state and nationally

Build Recovery Orientation into On-Going System

- Mandate recovery training and integrate into basic and advanced strengths model training
- Examine how recovery can become part of
 - RFPs,
 - managed care,
 - strengths assessment,
 - Client Status Report etc.

Build Recovery Resources In The Community

- Identify how faith communities can be involved
- Improve access and build accommodations through supported education, work, parenting and housing
- Public education on recovery