

RECOVERY
THE NEW FORCE IN MENTAL HEALTH

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RECOVERY

The concept of recovery has been common in the field of physical illness and disability, however, it has not been commonly seen as a potential for people with severe a mental illness. Yet as we developed systems of comprehensive community-based services, which are based on a more thorough and clear understanding of the characteristics of mental health consumers, we are beginning to recognize their different needs and abilities. Consumers are using system to educate us about the impact of severe mental illness on their lives. What they and a handful of researchers and mental health clinicians are saying is that given the right support a recovery process is possible.

Mental health consumers describe the process of recovery as deeply personal and unique, involving changing one's attitudes, values, feelings, goals, skills, and/or roles. It is a way of living a satisfying, hopeful, and contributing life even with limitations caused by the illness. That it is possible to be "in recovery" even though the illness is not "cured".

Enclosed is a set of articles from consumers, psychiatrists, and mental health administrators. They discuss recovery from each of their perspectives as the mental health system incorporates the concept of recovery as an integral part of the treatment process.

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Recovery: The New Force in Mental Health

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A wind is blowing across the field of mental health. This wind has occasionally been felt by people with mental illness, by families, and therapists. But it is gathering strength now in the consumer movement and in communities. I believe this wind will become so strong that it will bend or break the “mental health system.” Tonight I want to describe this force, and challenge you to feel it, finally join and move with it.

Its early stirrings were noted and written down by mental health professionals and researchers a decade ago. By this time, we had been sensitized that hospitals were not for all. That serious mental illness is a long-term affair and that community support is the way to go. Describing their experiences working with people with the most serious, psychotic symptoms, psychiatrists Alan Brier and John Strauss wrote in 1983:

Self-control of psychotic symptoms is certainly not a panacea, but the evidence weighs heavily in favor of it being a relatively common phenomenon, and one of potential importance for understanding and treating psychotic disorders. Through their use of self-control measures, many persons with psychotic disorders may have been among the first to apply what is practically a systems concept, the kind of conceptualization we have proposed as the most accurate model for understanding the processes central to these disorders.

Brier and Strauss et al, 1983

But other clinician/researchers had noted something too. A team of rehabilitation researchers led by Dennis McCrory had noticed that people in rehabilitation who clearly were getting better still experienced crises. They felt these crises were not necessarily a step backwards and wrote:

The “rehabilitation crisis” is the experience of the disabled person who has accepted the challenge to grow, has achieved significant movement toward his goals, and is now feeling overwhelmed by his changing/changed state. The client has advanced far enough in the process to begin to experience a transition in his activities, his relationships, and his sense of himself. He is proud of his progress, yet sad for what he must give up and frightened of the uncertainties he must face. He is in conflict and must choose to go forward or return to his previous state. He is giving up old ways; he has yet to establish new ways. He is in transition and he is vulnerable.

McCrory et al, 1980

The early ‘80s marked a time of movement toward the community support model. Usually such “paradigm shifts” come ahead of research results—as opposed to the traditional view that research leads to change. And this occurred as the CSP approach was being adopted. At the same time, researchers were discovering that the long-term prognosis for people with schizophrenia was better than

thought. In a Vermont study, 200 people who had been “back ward schizophrenics” were interviewed 20-25 years after their discharge from the state hospital via a model rehabilitation program. For fully half of these individuals, their mental status was indistinguishable from age group peers who had never been diagnosed mentally ill. Keep in mind all of these individuals were so called “chronic schizophrenics.” Summarizing their results, the researchers noted

...in each of the five major studies conducted in this last decade which assessed the long-distance outcome of schizophrenia, more than half of the subjects were recovered or significantly improved in their function. Together, stance of rational optimism from the demoralizing pessimism which pervades case conference, plenary addresses at national meetings, influential journal articles, and consultations with families of patients.

Harding et al, 1984

Can you see how new beliefs are developing?

Other evidence supporting a positive view that came from clinicians who found that people with mental illness—far from behaving like passive “patients”—worked hard at and were very skilled in living with and managing their disorders. Clinicians in New York surveyed 86 people with schizophrenia, asking about coping strategies they used. These “seriously” mentally ill people identified over 1,500 coping strategies which they used to help manage their symptoms.

The story so far is that mental health professionals and researchers were starting to say, “Something’s happening here.” Fortunately, in the past decade, the real experts have come out of the closet and started to speak out. One of the most brilliant witnesses is Esso Leete, a woman from Colorado who in her words “happens to have schizophrenia.” Listen to her words and you will hear the power of new understandings.

I am a person, an individual, a human being. I happen to have schizophrenia. For 25 years I have lived with and in spite of it, struggling to come to terms with my illness without giving in to it. I have been hospitalized fifteen times, the longest hospitalization lasting a year. I have had twice as many doctors. I have had ten diagnoses (most of them variants of schizophrenia), I have been prescribed nearly twenty medications, and have had almost every kind of therapy imaginable, including seclusion and 4-point restraint “therapy,” as well as insulin coma therapy concomitant with E.C.T. In other words, I have been treated with everything for everything. Although I have fought a daily battle, it is only now that I have some sense of confidence that I will survive. Yet mere survival is not enough. I have been asked what makes life valuable and enriching to us as people. My answer is: “We need to feel wanted, accepted, and loved. We need to be productive. We need leisure

pursuits that gratify us. We need support from friends and family and a sense of stability in our environment. We need to be accepted by and welcomed into our communities. We need to feel a part of the human race, to have friends. We need to give and receive love. In other words, our need for a quality and satisfying life is no different than anyone else's."

There is no doubt that the presence of major mental illness can shatter lives, yet it is important for professionals, family members, and us as clients to realize that there are steps we can take to minimize the effects of a mental illness and to live productively. As we encounter the inevitable daily hassles, we must deal with them constantly experience, an opportunity to make sense out of our world and our relationships.

And although I do not have formal educational credentials, I feel I have become somewhat of an expert in the area of my illness. Having lived with it these many years, I now have a personal understanding of it that could never have come from books or degrees. Recognizing and building on our assets, our strengths, is the most important step we can take on our road to recovery. And one of our most powerful strengths is our ability to develop coping mechanisms for dealing with our disorder.

Leete, 1992

These words communicate hope, competence and effectiveness. They make me think "what an exceptional individual.' But Esso Leete is far from being alone. In fact, the many people recovering from mental illness are not alone. Another psychiatric survivor who is a talented writer is Pat Deegan from Massachusetts. She studied recovery by interviewing a leader in the Massachusetts Independent Living Movement of people with physical disabilities. Here's what was said by Charlie Carr.

Now for me, that was the beginning of regaining control. It was not easy to gain control over my life again. It was very difficult. Some things came very naturally but some things didn't. One of the things I had to learn is that with control comes sacrifice. In order to be in control you hadn't thought that through very much. But I did have to rely on people and I still do. I also got to realize that everybody relies on somebody, somehow, for something. Even though I had been relying on nurses and attendants and staff for years, they really had all the power and all the control over me. But now it was different. I still relied on people but now I decided who I depended on. I decided what I wanted to do, what I wanted to eat, etc. I had no choices when I was institutionalized. Regaining control over your life. That's the key.

Charles Carr in Deegan, 1992

Here is Esso Leete again.

Sadly, for years I had expected someone else to “fix” me. However, I finally realized, after many clinical disappointments, that this task fell to me alone and that no one else could really make me better. I approached this task very seriously, conscientiously working to get my life back together. For the first time, I then felt ready to take responsibility for myself, including management of my illness, and it was at this point that my recovery really began, I think.

Leete, 1992

She goes on to say:

We are learning to rely on ourselves and to take an active—and creative—role in our recovery and in our lives. We are empowering ourselves. If we periodically fail in our efforts to achieve this, then let us fail. But we must be given the opportunity for success as well. We now know that persons with a psychiatric disability can recover if given the change—and we have a right to that recovery. The gift we can give the world is the knowledge that mental health clients can change, that we can contribute, and that we CAN RECOVER.

Leete, 1992

This is powerful stuff. It raises major challenges for a mental health system and for each individual provider.

What is our role as mental health providers to be? Fortunately, people are giving us the answer. But it all begins with a bottom line, articulated by Dr. Ed Knight who directs the Mental Health Recipient Empowerment Project in New York.

Rehabilitation is the process of putting a broken life back together. This must be done by the person whose life is broken. Techniques can be suggested, but the person in question must do the work.

Knight, 1991

And, Esso Leete again:

Let me briefly summarize what helped me in my own recovery process. Being seen as a person, not a diagnosis was of course the first step. Finding professionals who recognized and respected my differences and individual needs was crucial to my recovery. I found acceptance and reassurance more helpful than confrontation. Social skills acquisition enabled me to successfully reintegrate with my community. Vocational skills led me to employment. Crucial was a strong orientation towards success, with treatment focusing on healthy and adaptive aspects rather than deficits. As a result of my developing confidence in myself, I was

able to grow and achieve independence. Indeed, I have gradually—but finally—learned that I myself am my greatest asset.

Leete, 1992

So, there is a clear role for mental health professionals. Lots of support is needed. But, for many individual staff members (therapists, case managers, and psychiatrists) this is a familiar message. Good clinicians practice these skills and live with these values everyday. The real question is—is our mental health system structured to support recovery? And the answer is not! Too often we create what Pat Deegan calls a cycle of despair and disempowerment:

The Cycle of Disempowerment and Despair starts with

The Central Attitudinal Barrier

People with psychiatric disabilities cannot be self-determining because to be mentally ill means to have lost the capacity for sound reasoning. It means one is irrational and crazy. Thus all of the thoughts, choices, diagnosed with mental illness can be ignored...

The System Takes Control (for the person's own good)

Therefore professionals within the system must take responsibility for us and our life choices...

Learned Helplessness

As we become experts in being helpless patients, the central barrier are reinforced...

The Prophecy is Fulfilled

Deegan, 1992

But the wind of the recovery vision is blowing away this cycle. And as the air gets clearer, we can learn some other things.

The first lesson is about hope. The cycle of despair must be replaced, to borrow Courtenay Harding's term, by "rational optimism." This lesson emerged from a dialogue among consumer survivors and psychiatrists in New York, brought together to explore these issues. In a paper on this prepared by Andy Blanch and others for the American Psychiatric Association, one line stands out:

Hope is perhaps the most fundamental factor in recovery.

(Blanch et al., 1993)

Unless every individual in the system starts with an attitude that conveys hope, the rest is not relevant. But there is more.

It is clear that the skills and even the programs of the mental health system are essential. Well, most of them are essential. Remember what Esso Leete said about rehabilitation, about counseling. And although we do not need a rigid medical model that sees people as simply ill, we desperately need to provide good care delivered in partnership with people.

One of the clearest thinkers in our field is Bill Anthony of Boston University, the “godfather” of psychiatric rehabilitation. In the April 1993 issue of the Psychosocial Rehabilitation Journal, Anthony proposes that the vision of recovery from mental illness should be the guiding vision for the mental health system for the 90’s. In it he points out how recovery is a process and experience we all share:

Recovery transcends illness and the disability field itself. Recovery is a truly unifying human experience. Because all people (helpers included) experience the catastrophes of life (death of a loved one, divorce, the threat of severe physical illness, and disability), the challenge of recovery must be faced. Successful recovery from a catastrophe does not change the fact that the experience has occurred, that the effects are still present, and that one’s life has changed forever. Successful recovery does mean that the person has changed, and that the meaning of these facts to the person has therefore changed. They are no longer the primary focus of one’s life.

Anthony, 1993

All of this describes the new wind of hope and recovery blowing in mental health. It raises the question of what a mental health system would look like if built on this foundation.

Here are the basic precepts that Bill Anthony describes: Do you agree with these basic points?

1. “Recovery can occur without professional intervention. The task of Professionals are to facilitate recovery; the task of consumers is to recover.”

In particular, this makes it clear that we must move beyond “community mental health” to living together in the community. Families and non-mental health institutions are as or more important than programs. As Anthony points out:

“There are many paths to recovery, including choosing not to be involved in the mental health system.”

2. “A common denominator of recovery is the presence of people who believe in and stand by the person...”

We know this is true. And who stands by people? Family and friends, that’s who. How effectively do we support families, friends and peer support?

3. “A vision of recovery is not a function of one’s theory about the causes of mental illness.”

Recovery is bigger and more complex than “cure.” It is something people do for themselves. People can recover even though their illness gets worse.

4. Similarly: recovery can occur though symptoms reoccur.”

This happens with other conditions as well, like arthritis or Multiple Sclerosis. A good example of a recovery strategy is people negotiating advance directives for how they want to be treated if their symptoms go out of control.

5. “Recovery changes the frequency and duration of symptoms.”

In the recovery process, symptoms may actually get worse, as pointed out by McCrory et al. But with recovery, symptom recurrence is less of a threat.

6. “Recovery does not feel like a linear process. Recovery involves growth and setbacks, periods of rapid change and little change.”

John Strauss’ research confirms this. He notes the many paths of recovery that individuals take—the “low turning points” and the periods when people are gaining strength and trying new behaviors when it might appear that little is changing.

7. “Recovery from the consequences of the illness is sometimes more difficult than recovering from the illness itself.”

In fact, for many people recovering from the consequences of mental health care is harder than living with the illness whether these consequences are stigma, institutionalization, abuse, or just having no one who has hope in you.

8. “Recovery from mental illness does not mean that one was not “really mentally ill.”

This reaction is just another part of the self-fulfilling prophecy of despair. But it is not true.

If these are the key aspects of a recovery-based mental health system, what are we to do?

It is the time for us to systematically use the recovery paradigm to reshape our system. I believe our basic assumptions and paradigms have been wrong. From the medical model to the bio-psycho-social approach to rehabilitation, we have been too strongly focused on what we would do to people. I am suggesting the paradigm of recovery as the most basic premise of what we do with people.

A transformation to a recovery-based system is not like the move from hospital to community. It is the move from community mental health to living in community. It means each agency program and individual must bend or move to the new wind. Here is how Bill Anthony describes it:

A mental health services system that is guided by the recovery vision incorporates the critical services of a community support system organized around the rehabilitation model's description of the impact of severe mental illness—all under the umbrella of the recovery vision. In a recovery-oriented mental health system, each essential service is analyzed with respect to its capacity to ameliorate people's impairment, dysfunction, disability, and disadvantage.

Recovery-oriented systems must structure their setting so that recovery "triggers" are present. Boring day treatment programs and inactive inpatient programs are characterized by a dearth of recovery stimulants. The mental health system must help sow and nurture the seeds of recovery through creative programming.

Anthony, 1993

We must look at our entire system from this viewpoint. It goes beyond a few consumer controlled "alternatives," a few consumers and family members on boards, and business as usual for everyone else.

But you already know this. In a recovery oriented system, every admission to a hospital, for example, would be used as an opportunity for change, not as a crisis to be weathered. We would move beyond "maintenance" treatment to actively working to help people control their lives. Instead of giving a few consumers power by appointing them to boards and councils, we would empower every consumer to control their own life. We would listen more to what people want, and a little less to what we think they need.

History says that individual people are far more able to heal themselves than the mental health system is. So I will close with the challenge and prediction that a consumer leader (Esso Leete) has provided.

The mental health system will now change until it absolutely has to, and thankfully, that time has finally come. No longer do mental health clients feel powerless: forced into treatment, coerced into power struggles, and administered therapy that others have determined to be in our best interest. We are changing the image of whom we are and who we can become.

(Leete, 1992)

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RECOVERY:

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ABSTRACT

This paper addresses the concept of recovery as it relates to person characterized as having major mental illness. The author is a consumer who has also worked as a mental health provider.

An attempt is made to carefully define the terms “treatment, empowerment and recovery.” Mental health programs which are more apt to facilitate recovery are described. Traditional practices which militate against growth are also discussed.

Factors which relate to ways in which systems make changes, as well as how providers within systems may change are also discussed.

Biographical

Garrett Smith, MPA, was until recently Executive Director of The Mind Empowered, Inc., a consumer/survivor operated mental health agency in Portland, OR. He is now the state-wide Director of Consumer Advocacy in Oregon. Both conceptual and editorial assistance was generously provided by Daniel Fisher, M.D. Director of the National Empowerment Center of Lawrence, MA and Robert Nikkel, MSW, of the Oregon Mental Health and Developmental Disabilities Services Division.

WHAT IS A RECOVERY PARADIGM?

Recovery is a phenomenon which all persons experience, as is growth. We cannot get very far considering the concept of recovery if we start with the tools of medicine and the mental health system and go looking at ways to use them. We need to consider what a person may need and may be asking for in order to determine whether we have anything to offer them in their journey.

Persons who have experienced major mental illness may perceive that their opportunities for growth have ended. The idea of “recovery” for themselves as humans may at first seem out of the question. This may result from their own conclusions or it may come about from the signals received by those who constitute their environment and feedback system.

This paper addresses several questions posed to a number of responders. Perhaps I was included in part because: I have a mental illness which has been labeled bi-polar. I am also an alcoholic who has been “dry” for eleven years and who is a past and current participant in the twelve step “program of recovery” of Alcoholics Anonymous. I’ve been in psychiatric hospitals, been homeless, been employed, been married, been a parent, been a mental health provider and advocate and have “been” a lot of other things which fall within the normal range for fifty eight year old men.

Before addressing additional questions about recovery and the mental health field, it seems to me useful to further define some terms we use. Though there is some linearity in this discussion of stabilization; goal setting; empowerment; recovery; it is not at all clear that a person cannot engage in more than one of these activities simultaneously.

- I. CRISIS: Persons with whom providers in the public mental health system work usually experience severe “symptoms” at some early point of what is called their illness. Most of us believe that it is appropriate to make the resources of the medical and mental health professions available during such times. I have no doubt, that persons whose perceptions of the world have changed radically are particularly vulnerable and that our ability to reverse and/or minimize this often sudden change is desirable. Presuming, of course, that the affected individual agrees.

During such a time of vulnerability and dependence we usually focus our efforts on stabilization and don’t worry about much else except issues of safety. Talk of goal setting, empowerment and recovery may seem premature. But in the long run, as the economist Lord Keynes observed, we’re all dead, so we need to always entertain the possibility of growth in the face of continuing severe disability.

- II. GOALS: At some point persons being served by a mental health program usually, if not inevitably, are assigned to what we often call case management. Case Managers usually construct treatment plans. The consumer may be a passive or an active participant in this process. Central to most treatment plans are goals. Too often these are based on what the agency has to offer (take a look at your program budget line items). If we consider an individual as a whole person perhaps we don't see the majority of their agenda having anything to do with what we have to offer---nor do they.

To the degree that we are paternalistic, we can cut a person off from those broader issues in his life which are as crucial to recovery as are symptom control and showing up for day treatment. To the degree our services and supports are agency defined, growth for a human is proscribed.

As a person I too often define myself, for myself, in terms of the signs that I get from the environment in which I am. For a person with a major mental illness, environmental signals are particularly critical. After a major experience of loss we are very often without a clue as to where we may stand. We're seeking external definitions, the way mental illness is perceived by society and by those who train to assist the psychiatrically disabled has a profound effect on how person with mental illness view their future. And our views of our future can certainly determine today's institutional and community behaviors.

- III. EMPOWERMENT: We have been talking about empowerment for some time now. Very often the idea is misunderstood and misused. Let me strive to define what the notion means to me, for I believe it is a third force at work for the person who would be in recovery.

The number of times I've been asked by a mental health professional how they can empower somebody tells me, sadly, how off base our view of our own roles can become.

Let us revisit for a moment the very real disability that a person with a major mental illness experiences when symptoms are severe and out of control. At that time they are largely dependent, and power over their lives is vested in others. In Alcoholics Anonymous, Step 1 points out that alcoholic are powerless over alcohol; that their lives have become unmanageable. Acceptance of that notion never-the-less leads successful participants to a program of recovery.

Acceptance of major mental illness too often leads to acceptance of the idea of externally defined limits of disability and dependence. For me, the process of empowerment is happening when an individual is coming to realize and believe for him/herself that a psychiatric disability of whatever

nature and extent doesn't constitute permanent and total disability in all areas of life. And that further, it is reasonable and desirable to regain and maintain power over decisions, agendas and life itself to the extent one chooses.

This belief, entirely internal and "felt" or in time taken for granted, should and can be supported by the environments which mentally ill persons are often forced to inhabit, or choose to inhabit. One of the powerful affects of the consumer self-help and provider movements are the role model demonstration that recovery is possible and that, therefore, personal power is neither illusory nor lost forever.

- IV. RECOVERY: I would argue, then, that a recovery paradigm is simply a growth model within which an individual sets their own (and buys into society's) goals in the same manner that your two year old, your ten year old, your fifteen year old offspring---and you yourselves do. Someone in recovery is just "getting on with it"; just "getting a life".

You will recognize that to some degree I've forced a four phased process description on sets of phenomena which can and very often do overlap. In fact, we need to better understand and explore how and why recovery may be occurring in persons who are experiencing serious setbacks in their illness, per se. But as with the ideal of empowerment, the concept of recovery is a new and difficult one for many persons who have not had the experience of a major illness or a major personal loss. If we are to think clearly about our current ways of providing services and supports—and how they might be impacted and changed if we embrace recovery as a way of thinking and talking about an observable phenomena---then we need to be as rigorous as we know how in discussing our issues.

Parenthetically, many mental health professionals were extremely threatened by the idea of empowerment. Through their misunderstanding of the concept, they believed that an empowered consumer represented loss of power for the "provider". The bureaucratic part of all of us should know that roles are infinitely expandable. Relationships change, but if we are successful those relationships are now less useful or rewarding, only different. Recovery for me does now spell unemployment for you.

WHAT IMPACT WILL RECOVERY HAVE ON YOUR LIFE AND WHAT COPING STRATEGIES HAVE YOU USED IN YOUR RECOVERY?

Even if medical supports are needed on an ongoing or periodic basis, when one begins the recovery process all of the parts of one's world become potential resources in negotiating life and achieving goals. A person with a psychiatric handicap who has a sense of being empowered will want to be able to choose

from among available resources. They may not opt to cross the threshold of a mental health agency in this phase of their life. Supports which may be more appropriate or useful may be available on the streets, in church, at home, at employment offices, at work, in large malls, on the basketball court or in a book. As a consumer who sometimes has a lot of work to do if I am to function well, enjoy life and avoid a psychiatrically disastrous episode, I do not choose to use formally offered public or private mental health services today. I do work with a physician on medication strategies. In recovering as a person, in working toward feeling whole again, I personally choose to attend AA meetings of my choice on a regular and usually frequent basis. I have found other supports to recovery as well. Working as a provider in the mental health system exposes me to information, role models and personal supports which seem quite special to me. Using our sub-set of language, this translates into "recovery oriented self-help". When "getting a life" supersedes "getting a drink" or going to day treatment in importance, then growth or recovery agendas begin to look alike, no matter what the disease to which they may have originally been attached.

WHAT IMPACT WILL RECOVERY HAVE ON SERVICE DELIVERY? and HOW CAN CLINICIANS INTEGRATE THE CONCEPT AND PROCESS OF RECOVERY INTO TREATMENT?

Historically, of course, mental health treatment has been prescriptive rather than consumer driven. If we are truly able to succeed in understanding what human recovery is, and if we as providers of mental health services are able to let go of or suspend out traditional ways of thinking about "treatment for the mentally ill", then there should be major impacts for both programs and providers.

One reason for defining four stages from dependency to recovery at the beginning of this paper was to enable us to differentiate between needs based on program considerations and needs which are perceived by individuals in recovery. Most of the following remarks have to do with person who is at least capable of feeling the stirrings of personal empowerment and subsequent steps of recovery.

It is useful to use the family as an analogy, without in any way wishing to infantilize the disabled person. Though we think in terms of growth when we think of what children do over time, my argument is that growth and recovery are essentially the same process whether one is experiencing it as a normal part of growing up or in response to a devastating personal loss. The parent-child relationship alters as growth occurs. The child wants, advocates for and hopefully gets increasing independence. The transfer of governance from external to internal is a struggle. It is negotiated. It follows a herky-jerky course. Failures and setbacks occur. BUT, for a normal child, this growth is considered not only desirable but inevitable. If recovery is possible for persons who have been afflicted with what we call a major mental illness, then it seems to me

morally imperative to argue that the psychiatrically handicapped have as much right to aspire to full emancipation as anyone else.

It is interesting to me to reflect that the concepts of "intake" and "assessment" are central to community mental health. I'm not sure we have even invented the language to describe graduation.

We delude ourselves, I think, because we know that major mental illness very often has elements of chronicity. We need to think about the possibility that symptom management and recovery (or self management) can triumphantly fuse. Or perhaps symptom management and recovery are separate and unconnected, as Kenneth Thompson, M.D. of the Western Psychiatric Institute and Clinic recently postulated. Quite obviously, clinicians can be enormously helpful to individuals who are moving in the direction of recovery. Many parents find it hard to encourage their children to go off on their own. Case Managers sometimes have trouble when it is time to stop managing their "cases".

Another element in this dynamic which has to be examined has to do with the need and expectation that a part of the recovery process involves the individual taking responsibility along with control.

It has been my experience as a consumer/provider that those who would care for the mentally ill have a difficult time confronting us consumers when we are acting unreasonable or irresponsibly.

It is very often both reasonable and desirable to think in terms of reasonable accommodation. Neither family members, clinicians, nor society in general should have to apply different standards of responsibility to a consumer/survivor who is operating within an area of competence. In fact it is counterproductive to growth in either the child, the psychiatrically handicapped or any human being to not insist on accountability.

The questions of what impact the concept of recovery will have on service delivery and the behaviors of clinicians as a global question creates difficulties for those who would seek simple answers. Part of the difficulty lays in the variety of service delivery models we employ. The variability of mind sets is also large: the training professionals get; the intellectual flexibility and daring of administrators; the median age, perhaps, of direct care workers and the clinical supervision which they receive; the organizational philosophy and the degree to which clients are already empowered will all influence the impact of the recovery idea if it is rigorously embraced.

Surely some service delivery models are more "recovery friendly" than other. If we're serious about incorporating the principles of recovery into mental health systems, we need to look at mental health programs in terms of their existing recovery components.

The model about which I know something, which is in widespread use and that seems to me to hold the most promise is composed of two elements: the first is housing of choice; the second involves supports that are provided “in situ”—or in the community, if you will.

The term “outreach case management” capsulate the concept of providing supports to persons in their environment, where recovery actually takes place. More than twenty years ago, in Wisconsin, the P.A.C.T. model embraced outreach support. Now, of course, the Bridges Program in Chicago, the states of Delaware, Rhode Island and many others employ community supports integrally.

More recently, many have embraced the assertion that persons with mental illness have as much right as anyone else to live in housing of their choice, and those services and supports should be available to persons who opt for their own apartments rather than group homes, for instance. Paul Carling and the Center for Community Change through Housing and Supports have been powerful proponents of this set-up for empowerment and recovery.

Three years ago the agency with which I am associated, The Mind Empowered, Inc. was invited to identify thirty persons who had lived in our state hospital for at least a year and for whom earlier attempts at community placements had failed, if they had been tried at all. Many of these persons had been in the hospital for years. All were judged by hospital and community mental health staff as too disabled to live in the community in any setting, much less in housing of their choice.

When we asked the thirty people who chose to work with us where and how they would like to live if they were to leave the hospital, they almost universally replied that their ideal would be to have their own apartment. We worked to help them find reasonably safe, affordable housing. Our consumer/professional case managers then offered whatever services and supports (including psychiatric services) that the client wanted and that seemed pertinent to maintaining the goal of community living. For the persons in question, just not having to go back to the hospital was in most cases the overriding initial goal.

Community tenure increased dramatically.

The powerful and clearly observable phenomena with most individuals who had been languishing in the hospital for years, however, was that human beings began to grow and recover in remarkable ways. They did more than maintain. Most want and need fewer supports. Most have developed relationships not dependent on those constructed for them by a mental health system. A few work. Some fired their case managers. After all, their case managers were and are themselves powerful examples of recovery at work.

It would be my argument that an environment where growth and recovery were possible triggered the start of that process. The program itself proclaimed to individuals that others believed in their capacity as human being to “get a life”, to take responsibility, to change. Hospitals and other inpatient facilities, including many group homes, have back doors that are too often tightly shut.

Many clinic based programs attend only to medical (symptom) issues, what has been called talk therapy and peer socialization programs which lack recovery oriented role models.

WHAT DOES THE MENTAL HEALTH SYSTEM NEED TO DO TO SHIFT THINKING AND SERVICES TOWARD A RECOVERY PHILOSOPHY?

We need to start listening to consumer. When asked, persons with major mental illnesses always place housing and employment assistance as the two most pressing needs for those, not in psychiatric crisis. Supports designed to help persons achieve and maintain these goals are sought.

There is nothing startlingly new in this observation, but even when consumers are heard, the mental health programs funded to serve them don't seem to change as they might. Many state and local programs have developed value statements and written system goals that were they to be implemented, would create a revolution in the look of the mental health field. The terms “consumer centered” and “consumer driven” have great currency but virtually no value as an agent of systems change. We have changed our language in many instances but not our practices. Too often we continue to provide what we think people need, rather than what they want.

I would argue that one of the barriers to change is that we think in terms of systems and programs, while recovery is a holistic phenomenon. The treatment of mental illness has been focused on medical interventions rather than community interventions. If recovery is to begin and progress for a person who has developed a severe mental illness, the person needs a supportive, positive and growth oriented environment first, rather than what we have come to think of as treatment.

There is no simple mechanism for fostering paradigm shifts within systems, programs or bureaucracies. The Mind Empowered's service delivery model, mentioned above, was based on widely available information that existing agencies had been unwilling to employ. We become highly invested in “our” way of doing things, especially when we continue to receive funding to continue those ways. In Oregon the State faced the challenge of limited funds and overcrowded institutions. Since existing mental health agencies were not sufficiently motivated to address these problems voluntarily, a new, flexible and largely uninvested agency was approached. Only after their response to the institutionalized

population proved useful were existing agencies willing to consider modification of their historic service delivery models.

The State mental health authority has further fostered systems change by entertaining proposals for community based programs which are designed to assist specific, identified individuals to leave out state hospitals. It is interesting and encouraging to see that many county and private agencies have been willing to design and implement programs which are experimental for them and are responsive to the needs of both the person stuck in non-recovery setting and the institutions which house them.

It would seem that we may adopt new catch phrases such as "The Recovery Model" but if that or any radically new way of doing our work is to actually be adopted, financial and other systemic inducements are likely to be required. If this is true, then powerful commitments are required in powerful parts of our mental health and political systems.

If system values, policy, planning and program development are held to be important activities within a nation, state or other unit of government; if the right constellation of planners are brought together; if strong leadership insists that implementation follow; if consumer participation and consumers' life goals inform the process, then I believe we can engineer significant changes. Should by that exercise we discover we want to.

WHAT LEGAL OR ETHICAL ISSUES COULD ARISE AS A RESULT OF THE RECOVERY PARADIGM?

It would seem that to the degree mental health providers take responsibility for the humans enrolled in their programs, they also assume both legal and moral responsibility for the decisions they may make which significantly impact that person.

It has been argued here that the recovery process required that an individual assume responsibility for his own "program". When that happens--- when the system becomes supportive rather than prescriptive---legal and ethical issues will fade. Clearly, the physician who prescribes medications will still incur liability. It is also clear that we all carry ethical burdens and must make choices when we are associated with a person whose illness results in their periodically experiencing reduced capacity to exercise responsibility for themselves. For a person in recovery, however, these issues are only a part of the picture, and mechanisms like advanced directives or living wills can further allow the recovering person to assume personal responsibility.

Speaking as a person with a psychiatric handicap and one who fancies himself as growing and recovering from the losses that disease can exact, it is my

personal goal to assume as much real and psychological power as my development allows. I'll take all the help I can get, but I want to be my own case manager.

William Lawson, MD, Psychiatrist

RECOVERY: IMPLICATIONS FOR TREATMENT OF AFRICAN AMERICANS

WILLIAM B. LAWSON M.D., PH.D.

Abstract: Recent pharmacological and psychosocial advances have made the concept of recovery more tenable for the severely mentally ill. Unfortunately historical precedence and current discriminatory treatment has limited the opportunities for improved treatment and recovery of African Americans. Current widely held beliefs in the African American community about mental illness and the mental health system often conflict with a recovery philosophy. However, characteristics of the African American family and community may enhance recovery. These cultural factors may give a clue as to why the outcome of severe psychiatric disorders is better in some third world countries.

The development of effective pharmacotherapy and the emergence of a concept of "least restrictive environment" as a policy goal have led to improved dispositions of the chronically mentally ill and virtually a rejection of the concept of "incurably insane". Recent advances in pharmacotherapy and improved psychosocial rehabilitation have now made the concept of "recovery" applicable to the severely mentally ill. Moreover careful longitudinal studies and better assessment techniques have shown that the severely mentally ill do not have the universally poor outcome that was originally thought. Nevertheless historical misconceptions and problems with accessibility of care have limited the application of a recovery philosophy to African Americans.

Historically, African Americans have been presumed to have more psychopathology and to be at a greater risk for the more severe and intractable mental illness. This view has been expressed in diagnostic patterns. African Americans have received the least optimistic diagnoses. African Americans were presumed to be at greater risk for developing schizophrenia and less likely to suffer from depression or mania. Assumptions of "weaker egos" were often used to justify this over-diagnosis. Moreover African Americans were presumed to suffer from the stress of increased opportunity and school desegregation. African American families were considered dens of pathology, which further contributed to family more and more severe psychopathology. Recent research, however, has shown that the over-diagnosis seen in African Americans is a result of misdiagnosis. Studies using structured interviews rather than clinical impression confirmed that African Americans were often misdiagnosed. As a consequence, individuals with disorders such as manic depressive illness or psychotic depression were probably deprived of treatment that would have led to a better outcome. Moreover the misdiagnosis often occurred in a milieu of expectation that African American patients should be "sicker". Such factors as racism, classism, and other factors related to social distance probably contributed to this lowered expectation since the treatment providers were invariably Caucasian and upper class in a mental health system that often mirrored a racially and socially separated society.

Treatment of African Americans in the mental health system has been consistent with the view that African Americans have more psychopathology and less likelihood of recovery. African Americans are more likely to be hospitalized. Moreover, involuntary commitment is more likely. These patterns are seen even when socioeconomic status is controlled. After admission this negative expectation continues. African Americans are more likely to be perceived as dangerous, to be placed in seclusion and restraints, and to receive more medication. Thus, the expectation of a poorer outcome is reinforced by treatment services less likely to maximize recovery. African Americans who are mentally ill may be disproportionately referred to the correctional system where mental health treatment may be inadequate or disregarded. The staff in mental health systems may not be as interested in promoting or expecting recovery. Less time is spent in discussing African American patients in treatment team meetings. Cultural issues are ignored or denigrated. African Americans are often not part of the treatment teams, especially as leaders. For example, African Americans make up less than 3% of all psychiatrists. African Americans are less likely to receive the more desirable dispositions such as rehabilitation services or case management and more likely to receive only medication or emergency room referrals. A vicious cycle is set up in which African Americans see the mental health system less as a place to promote recovery and more as a punitive system. Not surprisingly, African Americans either enter the mental Health system at a latter stage of illness or leave prematurely and against medical advice.

Persisting attitudes in the African American community also limit the opportunity for recovery. The mental health system is often viewed as a hostile which may limit the likelihood that the individual will maximize benefits. In addition, as noted above, many African American patients may leave treatment prematurely, especially if the therapist has negative racial attitude.

In addition, many African Americans receive limited information about mental health or recent advances. "Treatment" for personal issues is sought from friends, family, the clergy, or other informal providers. While personal and social issues may be effectively addressed, severe mental disorders may be ignored or inadequately treated; thereby limiting the opportunity for recovery. Many members of minority communities receive little information about mental health, and have little contact with the mental health system.

Moreover, African Americans are grossly/underrepresented, which further limits access to information about the mental health system. Consequently, antiquated concepts such as the "incurably insane", that nothing can be done about the "blues", or that the mentally ill are dangerous tend to persist. A key example was the public statements made about the recent suicide of a Washington D.C. legislature. They all emphasized the inevitability of the suicide and the hopelessness of ever doing anything about clinical depression. The concept of recovery was not considered.

Recent advances in pharmacotherapy have brightened the outlook for recovery. Agents, such as clozapine, have resulted in improvement in 30-50% of schizophrenic patients thought to be treatment non-responsive. Fluoxetine has allowed treatment of depression without many of the side effects, the anticonvulsants have become a positive alternative to lithium for mania, and agents such as clomipramine can effectively treat obsessive compulsive disorder.

These pharmacological agents are unfortunately not as available to African Americans. The proper use of these agents means that the appropriate diagnosis must be made. Failure of African American patients to receive the appropriate diagnosis can often mean the failure to receive appropriate treatment especially from the newer agents. New treatments are invariably more expensive, which will limit their availability to African Americans and other underrepresented minorities. In addition, African Americans disproportionately receive treatment in the public mental health system, which further limits treatment options since public systems are often under funded and more likely to limit pharmaceutical options. Special programs become more important for gaining access to new treatments, but African Americans are less likely to be referred to special treatment programs, especially research programs. Finally the lack of information about such treatments further limits their availability. Ironically, recent findings that African Americans may have more side effects with standard psychotropic medication due to pharmacokinetic differences and prescribing practices further emphasize the need for the availability of new treatments to this population.

More needs to be done to promote a recovery philosophy for African Americans.

- (1) Treatment providers must become cultural competent and to be sensitized to racial and cultural needs and to the tendency to differentially treat African Americans.
- (2) More needs to be done to educate African Americans, in general, about mental health.
- (3) Mental health systems must have better relations with informal provider networks in the African American community.
- (4) More needs to be done to insure that African Americans are not excluded from new or special treatment programs.

Some elements of the African American community may enhance recovery. Family members tend to be more tolerant, and supportive of the severely mentally ill. The African American family is often extended, with a number of informal contacts, which further provides an opportunity for non-institutionalized support. The role of case management in recovery has been often promoted, and the

already existing informal networks in African American communities can often be helpful.

Recent research has shown that outcome of the severely mentally ill is better in third world countries, especially African nations. One argument is that these cultures are less demanding or less stressful. However, another possibility is that while these countries are not as technologically advanced, they may be more socially advanced. Strategies may have been developed empirically that are superior to approaches used in developed countries, some of which may have been transmitted culturally to the United States African American population. In any event, the approaches of other cultures should be investigated to further identify approaches that promote recovery.

William B. Lawson M.D., Ph.D.

1. A recovery paradigm can best be understood when contrasted to alternative paradigms. The previous paradigms have been maintenance paradigms in which the assumption was widely held that the long term outcome of severe mental illness was a steadily downward course. Interventions were designed to, at best, prevent deterioration. If improvement occurred, it was in the context of extraordinary effort by the provider. The patient was considered passive. A recovery paradigm:
 - a. Assumes optimism and improvement or cure, rather than pessimism and deterioration.
 - b. Suggests that the patient can play a crucial role in the recovery from the disorder. The patient is not a passive receptacle of treatment.
 - c. Suggests increased adaptability and self sufficiency rather than increased vulnerability and passivity.
2. Recovery will have a substantial impact on mental health services. It:
 - a. Means that rehabilitation services must be provided rather than maintenance services.
 - b. Means that mental disorders are reversible and therefore a treatment investment is necessary.
 - c. Implies that aftercare must be addressed.
 - d. Mandates contact with families, employers, and landlords.

- e. Requires ongoing education, job training.
 - f. Means that the patient's social and cultural milieu must be taken into account.
3. Recovery can be integrated into treatment by emphasizing the need for Aggressive treatment, improving dialogue with the patient, close monitoring so that successes and improvements can be identified and enhanced not extinguished.
 4. Systems need to focus on developing independent and self sufficiency above all else, focus funding on a programs geared to success, remove elements that perpetuate dependency and passivity, reward innovation, develop rehabilitation services, develop cultural competence, develop better linkages to non mental health providers, and improve access to services.
 5. Legal or ethical issues include:
 - a. A redefinition of patient rights. Patients have the right to treatment. Conversely the failure to provide optimal treatment should be a basis for censure.
 - b. The focus should be shifted from the mental health system as a place to incarcerate people to a focus on getting people functionally back to the community.
 - c. The correctional system should not be the source of mental health services. Rather mental health services can be expanded to include individuals in the correctional system but the primary focus on mental health should be wellness.

Velma Beale

The Recovery Process From a Family Perspective

by Velma S. Beale

Dr. Johnson's presentation is well researched and professional, yet brings the personal perspective of a family member to bear on the recovery issue. I differ with him primarily on points stated in the first part of his presentation. These differences, of both a semantic and a philosophic nature, are, I believe, critical to our discussion of recovery.

I do not regard recovery as it is currently being explored as being equated with a cure. Recovery from serious mental illness is, in my view a process, not a point in time or an end result. I also do not believe it is productive to entirely base an exploration of new territory on the use of established maps. Rather than base our exploration of the recovery process entirely on previous, and often outdated, research and attitudes, I believe we must return to the source and remember that it is people with illnesses that we are discussing, not the illnesses alone. We should be speaking of recovering (a process) and of people in recovery (people controlling a process).

In the past all people with serious mental illnesses were viewed, with great justification, as being totally dependent on a system of care. Within the past fifteen years, research has yielded new medications and treatment programs with dramatic positive effects. As a result of these changes, increasing numbers of people are demanding more and more independence from the mental health system. However, as Steven R. Covey has pointed out, the goal in all interpersonal relationships should be neither dependence nor independence, but interdependence.

There are three groups of people with interests immediately surrounding the issues of treatment of mental illness: mental health professionals; significant others in the lives of people with mental illness, often family members; and most importantly, people with the illnesses. All should have a vested interest in promoting recovery, and should interact with one another with equal respect for what each brings to the recovery process.

As Amy Long stated earlier, "If recovery is seen as from within, the power is shared." She encouraged the "honest and open flow of feedback ...including times when providers may speak to their own pain or feelings of ineptness." In a recent article, Spaniol, Zipple and Lockwood recommend that mental health professionals be clear about the complexity of the disability and the limitations of knowledge and treatment resources. They suggest that professionals admit that they are also struggling to help. This awareness, it is stated, will help families come to terms with their own hopes, fears, and limitations, and prepare them to be partners in developing workable expectations and plans.

My youngest son is diagnosed as having paranoid schizophrenia. According to the DSM-III-R, as quoted by Dr. Johnson, "A return to full premorbid functioning in this disorder is not common." Nor has he. He still hears voices occasionally. He still experiences paranoia periodically. And it is sometimes difficult to determine whether his thinking is extremely creative or dysfunctional.

On the other hand, he has recently returned to college, been inducted into Phi Theta Kappa, the honorary society for two year colleges, married, and graduated with honors with a two year degree in computer programming. He plans to complete a bachelor's degree program in computer studies, has developed a commendable sense of responsibility as a husband and stepfather, and also manages his symptoms and medication in a highly responsible way. Even his negative symptoms have markedly decreased.

To say that he is not in recovery because he is still symptomatic does not seem productive nor related to his ability to function in the world. Yet, last week he told me that well-meaning mental health professionals, in his words, "keep telling me what I need and I keep telling them what I want. They don't seem to listen."

According to a study conducted in Lucas County, Ohio in 1993 by the Urban Affairs Center of the University of Toledo, the most compelling statement by family members was, "Listen to me." Family members felt that while they are usually no longer blamed, they are still locked out in their attempt to communicate with agencies. They felt they had something to contribute, and a desire to know the diagnosis, treatment plan, prognosis, and progress of their consumer relative. They would also like to be informed on the cause/effect of emotional dysfunction and how best to interact with their family member (including effective communication skills, procedures for improving compliance with the prescribed medication, and how to de-escalate high levels of anger). Families felt that confidentiality rules are applied differently by different people and are often a technique of avoidance. Families reported times that their consumer relative appeared to be over medicated or inappropriately medicated, and that they observed positive or negative reactions to medications, or that refusal to take medications was affecting behaviors, but they had no way to communicate these observations to the prescribing physician.

So far as, I know no mental health professional has ever asked my son exactly how he copes with the voices, which seem to occur in his most difficult class, or when he is most stressed near the end of a quarter. Yet he has developed strategies, including taking a tape recorder to class so that he can later listen to information he was unable to hear or concentrate on at the time. Once, he was walking through his apartment when the voice began on a low level. He assumed someone had the radio on and so ignored the voice. By the time he realized the radio was not on, the voice had ceased. He and his wife, who has atypical bipolar disorder, both have difficulty with memory. They have devised numerous strategies to deal with this disruptive problem.

It is these coping mechanisms that we must study to determine common characteristics, efficacy, and how each person individualizes the strategies. The question is not entirely how many symptoms have disappeared, but how people cope with those which still occur in order to increase their ability to function.

I am aware of current attempts to increase the options for developing coping strategies, including setting goals, relaxation techniques to reduce stress, providing information on how to improve interpersonal relationships, etc. Yet, how often are the strategies currently being employed by an individual evaluated and strengthened? How often is the individual encouraged to establish his own goals, regardless of available resources, or to develop her own coping techniques based on general suggestions? How often is the professional will to reevaluate his or her perspective on rehabilitation, treatment, medication or housing based on their client's expressed preferences or input from family members? We are all aware that not an extremely high percentage of persons with serious mental illnesses are highly functional at the present time, especially those with certain diagnoses, but it is important to study the coping strategies of those who are further along in recovery in hopes of helping others reach higher levels of functionality. In a realistically hopeful vein, we can most likely expect that with newer medications, more and more people will benefit from the knowledge gained from such research.

Ms. Long referred to the need for "connection" and Dr. Johnson pointed out that families often become the last resort for connections with the rest of the social world. It seems increasingly clear that peer and family support are the cheapest, most readily available, and most influential sources of support in the recovery process. Who "provides" between appointments? Who is there first in crisis in the middle of night or on a weekend? Who deals with the multitude of day-to-day problems, especially in the early stages of recovery? Where there is any relationship at all, it is usually a friend, lover, or family member.

I most heartily agree with Dr. Johnson that it is strange that these people are given so little attention by mental health professionals when they are such an important part of the lives of their clients, and therefore have a significant impact upon the success or failure of treatment procedures.

In my role as president of a community affiliate of the Alliance for the Mentally Ill, I have talked with many people who are trying to understand and cope with mental illness in themselves or a loved one. It has been my observation that they all go through similar stages from denial to recovery. I have also observed that there seem to be three major stages of a family recovery process. In the first stage are families who choose to remain in denial whose approach to their ill family member is always, "There is nothing wrong with you. We don't have mental illness in our family. The neighbors would think less of us if we did. Either straightens up, or goes away and don't embarrass us any further." Second stage families say, "Yes, you have a serious mental illness. You will

never be able to live a normal life. Let us tell you what to do from now on. We only want to protect you.” Some of these families are also extremely sensitive to the stigma of mental illness. Third stage families say, “Yes, you have a serious mental illness. We want to learn as much as possible about the illness including medications and their side effects, treatments, coping skills for families and consumers, and available resources for all of us so that we can help you to recover to the best of your ability. We will learn to let go as you progress, but will be there for you when you are in need for as long as we are able. We will advocate for more research, for better treatment programs, for improved laws and increased public understanding so that your chosen life will be available to you. We will also get on with our own lives.” Third stage families usually grow out of the first two stages through education, support, and their own enlightened concern. It is not easy for them, and mental health professionals who are open and supportive of families—who provide training and understanding without viewing the family as patients—can be extremely facilitating. It often requires patience, but it can be very worthwhile. The National Alliance for the Mentally Ill arose out of the unmet needs of family members for this support, but NAMI alone cannot solve the problem of involving families in the planning stages of treatment and rehabilitation.

Mary Ann Beall (no relation), consumer member of the **NAMI** Board, writes in the March/April issue of the ***NAMI Advocate*** about how the present practices of confidentiality contribute to the perpetuation of stigma. She says, “Where truth is kept secret, lies and half truths can prosper. The practice of confidentiality gives truth to the lie that serious mental illness is so terrible, and we who suffer from it are so unspeakable, that even basic information must be kept secret. Confidentiality erects the wall outside of which stigma can flourish for as long as the full truth about mental illnesses and what people like me really experience, remain closely kept, professionally guarded secrets.”

By failing to provide “even basic information” to family members or others significant in the life of the person with mental illness, stigma is perpetuated, the family’s recovery is retarded and whatever support they are able to provide for the ill person’s recovery is seriously hampered.

Dr. Johnson’s description of family psycho education which provides education and also includes family and patient together in problem-solving and coping skills training over a period of time, and the intervention form of family consultation sound like excellent ideas, but only if professionals avoid a systemic approach to families as being pathological. The role of the professional should instead be one of instructor, facilitator, and personalized consultant.

A tremendous amount of stress is generated by simply living day-to-day with mental illness, and sometimes just getting through one more day is all we can handle, whether the illness is our own or our loved one’s. Any program that can reduce stress is beneficial to all. Any program that can help relatives promote

well-being and autonomy—help us to help without being intrusive; facilitate without being controlling, support without domineering—should certainly help reduce relapse and facilitate recovery.

I have often said that advocacy on behalf of my son and his family, and all people with mental illness, is therapeutic for me. I cannot cure his illness nor remove his pain. I can impact all the systems he must deal with so that he and his family will have better options. I can also speak up about the needs of community mental health centers when they cannot. This not only gives me meaningful targets for my anger at the illness, but benefits the system, all other mental health consumers, and my son and his family. Mental health professionals must learn to deal with consumer and family advocates as equals seeking the same overall goals, and as assets to the system. Spaniol, Zippie and Lockwood, in “The Role of the Family in Psychiatric Rehabilitation,” say, “Advocacy is a healthy response to the hopelessness that families often feel...Advocacy is also a natural and a necessary stage in the adjustment and recovery families.... Advocacy strengthens the potential for healing within families and within society.” They urge professionals, rather than feeling threatened to encourage and support families as they grow into advocacy roles. The same article encourages professionals to include families in planning and system monitoring groups, and provide input into program evaluation and human rights issues monitoring.

Recovery is growth and human beings do not grow in a vacuum. They do not even survive. It is well know that babies will die for lack of human connections. They can be fed and changed and medicated, but without the interactions with other human beings that make them feel connected to others in a meaningful way, they sicken and die. How can we assume that this does not have any application to adults, especially adults with mental illness? We certainly seem to whenever everyone meaningful to them is ignored when developing the treatment program and determining the recovery process. Family members can be the single most powerful influence in a person’s life. When I was about eighteen years old I went through a very difficult time and felt I could benefit from seeing a psychiatrist or psychologist. My mother’s reaction was: “Act your age. Pull yourself together.” Somehow I survived without intervention. I still think she was wrong to take that approach, yet I have always considered her the single most powerful influence on me in my formative years and well into young adulthood. What she thought helped shape my behavior and my approach to life. A family’s influence cannot be ignored.

Summary

Recovery is a growth process. Growth requires nurturing from various sources including medication, professional treatment, and facilitating support from meaningful others. Recovery is, however, an internal process controlled in the final analysis by the recovering individual. Individual coping strategies are

extremely important components of the recovery process which should be studied and regularly applied to help others. Respectful interdependence and healthy connections can help prevent relapse and facilitate a speedier recovery process.

Amy Long

Reflections on Recovery

Amy K. Long

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ABSTRACT

Working as a Consumer/Practitioner has given me a unique perspective on the system and changes that I believe need to be made in order for service delivery to be more effective. Words such as recovery and empowerment are both feared and revered. This paper seeks to allay some of those fears and speaks to recovery as an internal shift that includes the need for collaboration through connection between consumers and providers. Empowerment therefore is a natural outcome of this joint venture and addresses the need to equalize the existing power differential.

What is Recovery paradigm?

Recently I heard a preacher speaking on the importance of community and he struck a very deep chord inside me when he said “that those who will survive the 90’s and the turn of the century are only those who are in community”. In our world today we see the result of our struggle to find our voices, to have our careers, to be known as our own person, separate. Isolation and loneliness are more prevalent than ever before. We cannot and do not grow in isolation the way that we can in healthy community. Healing is about the re-joining once again of a wounded soul or spirit that has wandered away.

I could not help but relate this talk of coming back together again in community to my experience of my road to recovery. I live today with what some may call a mental illness, as somewhere along my road I was diagnosed and spent time on an in-patient unit of a hospital. I however, see it as I live with an emotional vulnerability. I also understand that this is an ongoing vulnerability that just as an alcoholic is told they are always an alcoholic, so my struggle is an ongoing process. For some of us life’s hurts and pains have been too much and have caused us to “flip in” or “flip out”, or to search frantically for some creative way to survive. At times, life here robbed me literally of my voice, and I found no words to communicate my need for help, to reach out, or connect. I was emotionally available to take on the pain around of others, both in my dysfunctional family and the pain around me in my world. In some ways it is as if some of us are born without an internal protective shield to keep us at a healthy distance from either the horror of our own situation or from the pain in the world in which we live.

To me, a recovery paradigm is each person’s unique experience of their road to recovery. There are similarities around themes or shared skills and experiences, but it is in fact a very individual experience which is not possible to etch in stone. It is more the embracing of the belief that recovery is possible and from that premise each person individually creating their own journey. My recovery paradigm included my re-connection which included the following four key ingredients; connection, safety, hope and acknowledgement of my spiritual self.

This brings me to the first key ingredient, that of re-connection. For me it entailed finding a person, a therapist or counselor who would meet me where I was at, take what I said seriously and communicate to me I was being heard and believed.

Once in a place of despair, I shared, when asked in a group, “what would your parents most like you to be when you grown up?” I said “dead”. The leader stopped, acknowledged me and repeated, “yes, dead”. I felt heard and believed, even though he had never met me and knew no more.

Out of deep pain and tears a number of years ago, I was only able to speak to my disconnection and confusion by saying “that the shoes”, which were on the

floor, each facing a different direction, “were confused”, and the flowers on the rug which were in a row with inches in between, “were lonely”. When I was most troubled, I could only speak to that outside me, I did not say it in the “normal way”, in the first person. But healing began as I found those who heard me, validated what I said; even when it seemingly made not sense, and even encouraged me to keep speaking. They encouraged my voice in any form, rather than trying to shut me up, or quiet me, as they held my tears and waited, while like a flower I slowly unfolded, in my own time. Reconnection or connection for the first time is needed for growth to happen, for life to be sustained and flourish. This is not so unlike the experience of a nurse who holds a failure to thrive baby and looks into their eyes while holding their bottle and feel the baby using them as a connection to encourage life so that they can physically thrive and grow. Connection is imperative to growth.

This brings me to the second key ingredient on my road, that of safety. Once connection or reconnection in my case, was made, then safety needed to be provided to do the work that I needed to do. A big component of safety includes sensitivity to language, to labeling, to the words we use to call others, and attention as to what we call ourselves. The words we speak, can either promote health and hope, or chronicity and doom. Language so clearly can either heal, or worsen how a person feels. The words chosen and uttered can either encourage someone like myself to return and stay present, or make it clear that in order to be safe I must stay out there. I had a therapist once who referred to the beginning process in therapy, the time the rules are talked about and negotiated, and the stage is set for the work that needs to happen, as a time of “nesting”. Much likened to when a mother bird is readying the nest for the birth of her babies. That spoke to me deeply about the importance of safety.

My recovery consisted of seeking out people who approached me as a person first, not a diagnosis. I refused to internalize my diagnosis, to see myself as a person who was fully described and known by some label that professionals were choosing to put on me. It felt very hard to be labeled, disempowering to feel little to no input as to how that label was reached, and even harder to see it written next to my name, as it made me feel hopeless and boxed. So in many ways I dared to recover in spite of my diagnosis, for I held onto the faith inside, as I knew that I was much more.

This brings me to the third key ingredient on my road, that of hope. Hope must be kept alive in order for healing to happen. I often found that I had to keep it alive secretly inside me when all others around me were not sure. When others around me were busily measuring hope for me by external guidelines, like my history or my symptoms, rather than be my responsiveness or availability in the present. I was able to find a therapist at one point who would verbally tell me when I wished at times to give up, that he would “hold the hope, the faith” as it were, until I could take it back again, because he knew that I would return to reclaim it. That was powerful, as he did not deny the depth of my pain, and he

promoted health by conveying his confidence. I also saw, what strength it took on my part, to trust enough, to allow someone else to hold the faith, the hope for me, as for years I only held it for myself.

Another important ingredient of hope is the yearning desire to be part of again, and now so alone, or so different, than anyone else. I refer to it as the need to “normalize the experience”. Recovery felt hopeful for me when I started seeing that a lot of what I needed was not in fact so different than what any other human being also needed and yearned for.

A lesbian friend once shared with me when she returned from a march in Washington D.C., how moved she was, when on the elevator, she realized, that for once in her life she was “nine out of ten, not just one out of ten”. When I heard that, it rang true, I was looking to feel nine out of ten, one of, not so separate, to once again be able to tolerate feeling included.

The last ingredient is the importance of the spiritual component to each of our lives. I am not here to share any one way, but rather to give credence to, to honor that we have a spiritual self and that it is a vacuum if we choose not to fill it. My recovery was assisted in times of my deepest despair by my willingness to honor my spiritual self, my ability to look to someone, some thing outside of myself, be it a person or an object. Included for me in this, was the ability to have as some say, a “third eye”, an ability to step outside of the pain and see it, if only for a brief moment as first, from a distance. I found that at times I had to fight to keep the darkness and despair from overtaking me, when those around me, caregivers and professionals were reviewing my history, or counting my hospitalizations or checking my length of stay or discussing my diagnosis. I sought to work only with those who believed in me, who were willing to see beyond the immediate and trust that recovery was possible.

I believe that a part of spiritual growth includes forgiveness, a “letting go of”, or a conscious decision not to get stuck in the pain. Anger as we all know stirs and motivates, forgiveness on the other hand, makes way for further growth. As I let in forgiveness, it felt natural to now find more room inside me to be there with others in their pain.

I will never forget the pain, but the intensity has lessened over time, as I opened myself to the possibility of forgiveness. For me I knew that if I got stuck in the pain or anger, that I would not go much further on my road to recovery, but rather would spend my life only in my own recovery process. This would be seen as acceptable by other, but for me it was not all I wanted. Someone once told me that the Greek meaning of the word therapy is to “ride alongside in a carriage”. That spoke to what I wanted to move beyond the pain and be able to join with other.

What impact will recovery have on your life and what coping strategies have you used in your recovery?

I experience my recovery process as an ongoing process which will continue as long as I am alive. I often need to call upon the coping strategies that I have learned over the year.

Personally, I have found therapy valuable. The therapeutic relationship assists in keeping me centered and working on my reconnection. It is not either I am or am not connected, but rather a process of coming back that takes time and nurturance. I find that as I strengthen that connection in my therapeutic relationship, that then I dare to move that reconnection out into the world at large.

I have worked at knowing my symptoms and try to be aware of them. I know that for me sleep is an important element, so when I start to lose sleep, I find the aid of hot soaks, walks, exercise or if need be, a mild non-addictive sleeping aid helpful.

Further I find it important to have support at my work place where I have been openly hired as a consumer. I have belonged for some time now to a peer support group at work which consists of those of us who are open about being consumers and are now practitioners. I have found it helpful to talk openly in that group about how it feels to have been on both sides. It is a place where issues are stigma and disclosure or feeling symptomatic can be talked about and support can be gotten.

For me it also includes maintaining balance of connection with others and some time alone to read, write, and go for walks with nature and to center myself. I often get too caught up in the busyness of life and have to work at slowing down. I find that it is like getting caught up in a sense of having lost time and having to make up for it. I simply take at those times some distance or get a break, or give myself permission to take a day off, which helps.

How can the mental health system best assist you in your recovery process?

As for the mental health system today, it can best assist me in my recovery process by asking me and other consumers what does and what does not work. One way to obtain this information in a respectful way would be to set up more dialogue panels of both professionals and consumers where honest communication and listening can start to happen.

Another way would be including in the mental health system more options for healing. The system so often is much the same for everyone, if you have this symptom, you get this diagnosis and should receive this medication. There

needs to be more room for creativity and individualized plans rather than the “one size fits all” type of mentality.

Further I suggest that consumers be included at all levels of the system, not just as token board members. A number of consumers should be on all committees and given an honest and equal voice with respect and dignity. Opinions and participation by consumers needs to be sought after and valued and incorporated into decision making and policies.

I personally believe that if what I am talking about in the above paragraphs and preceding pages is embraced, there will be a tremendous impact on service delivery. So often today I hear top management resistant to talk of change or improvement due to the amount of budget cuts and financial constraints that they feel. I contend that what I am talking about has no extra dollars attached, and in fact would actually cost the system less.

If the concept that recovery is possible is truly embraced, there would be a lot of aftershocks to be dealt with. If providers got it that the change is an internal shift, their whole way of being with themselves and consumers would be very different and more healing would happen. It is moving from tunnel vision thinking to broadening the horizons of possibilities. Often it is difficult for providers to understand that ultimately healing comes from within, not from without. It is a way of being with consumers, not trying so frantically to find a treatment plan from without to affect change. Another piece that makes this so difficult is that when recovery is seen as from within, then the power is shared.

The late R.D. Laing pointed out in an interview with the New Age Journal in 1984 that the term “schizophrenia’ was coined by a Swiss psychiatrist in 1911, literally meaning “broken heart”. Laing himself referred to schizophrenia as a special strategy a person invents in order to live in an unlivable situation. On the other hand, the DSM 111 states that the prognosis for a person with schizophrenia is a “downhill course”.

If nurses and doctors in ER settings approached the room with a patient who has presented emotionally upset as if they are about to be with someone who is suffering from a broken heart, how much different would be their presence as they enter the room, rather than “there is a psyche case in the far room” and they enter defensively and annoyed. This is the internal shift that I refer to. Providers must see each person as a person first, who has been traumatized and offer to assist and join them on their road to recovery, letting them lead. Providers and consumers both need to recognize that the healer lies within each of us.

What impact will recovery have on service delivery?

If our service delivery embraced the idea of recovery being possible, it would not only include intake and assessment, but talk of moving on, life after the system. There are ways to enter and get involved in the system, but little time or energy is given on how to exit. We are all so much a part of a materialistic world where change only occurs from the outside, in contrast to where healing really occurs, from within.

There needs to be a way that when a consumer chooses to leave the system they are not seen as non-compliant, or diagnosed as borderline, but rather they are appreciated for the work they have done, their right to leave is respected and they are given assurance as they go, that the door remains open if they need to return. Service delivery must be respectful of the process of a consumer as they work toward caring out their own recovery path. Providers must be supportive, non-judgmental, and not seek to pathologize their choices.

When we shift to recovery paradigm, the barrier between providers and consumers would be lowered, and it would be harder to hide behind titles and desks as a way to protect oneself. There would be honest and open flow of feedback both ways, including times, when providers may speak to their own pain or feeling of ineptness.

Treatment plans would be more creative and include consumer agreed to goals after discussion, rather than goals that were selected for them. This would take time and effort on the part of clinicians, but in the long run, much less time, as the consumer would be able to achieve some of these goals, rather than energy being expended by clinicians to obtain compliance to goals that were not their own to start with.

Crisis plans need to be made collaboratively by consumers and providers at times when they are not in crisis, so as to be effective and helpful during their crisis.

Outcomes would appear more positive and statistics would show that consumers are getting better, not worse, because the goals would be achievable and agreed to, as they are stated goals by the consumers themselves.

This kind of service delivery would require humility and flexibility by providers and willingness to connect and to see and be seen.

What legal or ethical issues could arise as a result of the recovery paradigm?

Ultimately there must be sensitivity to legal and ethical issues. I know a lot of discussion is had around these issues, including boundaries and responsibility, but I want to start by saying that the risk is a lot less and shared if a real connection is made first.

An ER Medical Director of a prominent hospital in the Boston area was talking, as he did each year, with a class of new residents, who were looking to enter the field, and the issue of being sued was raised. This doctor shared a story at that point, telling how a few weeks prior, a man had come into his ER, and they made a friendly and respectful connection as they chatted about his work and life, both awaiting results of the x-rays of his hip. After examining the x-rays, he assured him he was okay, and sent him home with some medication. Later that evening, he was going over his files on his desk and the x-rays, and he noticed that the x-ray now he ordered, were not in fact what he had received. In looking at the x-ray now, from the angle that was taken, he saw that there was a hair-line fracture. He immediately summoned the man back to his ER. Upon his return, the man continued to be friendly and pleasant. He openly admitted the error to the man, however never in the course of his making amends, did the man mention wanting to sue him. He shared this story with his young residents assuring them that the best safety device against being sued was being humble, taking time with patients and being sure to make a good connection.

Another important area is that of supervision, providers need to be in regular supervision, where they can openly explore and know their feelings well. It is imperative they know their strengths and weaknesses and have support available when issues of the consumers with which they work touch them at their core. This helps avoid unnecessary struggles, power or control trips out of their own fears or pain.

Lastly, sharing the responsibility is an important part of minimizing the legal and ethical risks involved. As consumers are treated with respect and dignity, feel heard, empowered and validated, they in turn will at times even be eager to accept a piece of the responsibility for their own lives, thus lessening the load of responsibility so often carried by providers.

David Granger

“Recovery from Mental Illness:
A First Person Perspective of an Emerging Paradigm”

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ABSTRACT

A first person perspective of an emerging paradigm: Recovery as an outcome of mental illness. There is a growing interest within the field of mental health regarding a process of recovery from chronic mental illness. This article presents a first person perspective of a model of the recovery process, with a discussion of how individuals and social systems might be enriched by a more humanistic response to the issues and problems resulting from mental illness. The importance of reclaiming the mind, as the only link to the not-self, is the focus of an argument for recognition of the distinction between treatment of the person as object, and the recovery of the person as subject.

The Universe persists through the phenomenon of renewal which manifest as the activity of The Receptive. Also, man must learn to be receptive to what befalls him and use it as material for creation.

-- I Ching

(Wen, circa 1150 b.c.e. / 1980, p. 156)

THE CHAPTER OF COMING FORTH BY DAY, AND OF LIVING AFTER DEATH. Saith Osiris Ani: ... "Grant that this Osiris Ani may come forth among the multitudes which are round about thee; let him be established as a dweller among the shinning ones; ... Osiris Ani Shall come forth by day to do on the living." his will upon earth among the living."

-- The Papyrus of Ani

(Unknown, circa 1500 b.c.e. / 1967, p. 321)

A description of our process of thought demands on the one hand that an objectively given content be confronted with a contemplating subject, while on the other hand – as will be apparent from the very mention of it – not sharp separation between object and subject can be maintained when the concept of such separation forms part of our own mental content.

-- Neils Bohr 1922 Nobel Laureate for physics (Blaedel, 1988 p. 181)

WHAT IS A RECOVERY PARADIGM?

For me, what is implied in the recovery paradigm requires an entirely different way of thinking about life, the diverse struggles one encounters as part of the processes of life, and the very meaning of being human. These are perhaps pretty heavy philosophical issues, but for my part, these essential timeless philosophical questions are the stuff, the warp and woof, of what we are talking about when we talk about recovery. If your interest is only in balanced versus unbalanced biochemical system, quit this essay now, save your time and turn your attention to the study of cybernetics of some other model relevant to the control of lifeless matter.

Discussions of a new paradigm will ultimately require new concepts, and new terminology, but for now we must struggle along using familiar terms and concepts and allow for the stretching of our common understanding of these old constructs. Although Aristotle disparaged the use of metaphor for describing scientific phenomenon, modern understanding of systems have become so intricate that the use of models and metaphors is often essential for communicating an understanding of the phenomenon being discussed.

The problem of describing changes in the basic assumptions of a scientific paradigm using concepts and terminology of the previous paradigm resembles the problem of the farmer and the chicken coop. This particular farmer had the challenge to build a new chicken coop using the lumber from the old chicken coop. The problem, of course, is that he cannot tear down the old coop until the new one is built.

From the perspective of my personal experience, recovery is about surviving the destruction of self, as a co-creative human consciousness. Recovery implies not only surviving this disaster, but also doing the hard work of reclaiming the self as co-creative consciousness. Recovery signifies survival, reclamation, and return to the realm of socially constructed, consensual reality. Recovery is return, a return to culturally determined consensus renewed with a perspective of the self and the cosmos that is enriched by the integration of one's unique experience of "madness". It is a "COMING OUT BY DAY IN ALL THE FORMS OF EXISTENCE WHICH PLEASE HIM ... AND OF COMING FORTH AS A LIVING SOUL." (Unknown, circa 1500 b.c.e./1967, p. 280)

Cataclysm

The mental illness, that I experienced, was nothing less than a cataclysmic disruption of that most precious and essential feature of being human – sentience. In our culture the only concept we have for this drastic experience is MENTAL ILLNESS. "Denial", from the subjective perspective would seem

inevitable if not necessary. We would expect the same response if we were to inform a living being that she or he were dead.

- Don't tell me something is wrong with my thinking!
- What do you mean I have poor judgment and lack insight?
- YOU do not understand at all.
- I have fallen into some strange realm like Alice.
- Tell me something I can believe!
- Tell me this is the twilight zone or I have just entered Chapel Perilous.

Chapel perilous, like the mysterious entity called "I," cannot be located in the space-time continuum; it is weightless, odorless, tasteless and undetectable by ordinary instruments. Indeed, like the Ego, it is even possible to deny that it is there. And yet even more like the Ego, once you are inside it, there doesn't seem to be any way to ever get out again, until you suddenly discover that it has been brought into existence by thought and does not exist outside thought.... Chapel Perilous, as I said before is tricky that way. When you think you're out of it, you're just in another hall of illusions painted to look like the safe forest outside; and when you think you're inside again, you'll suddenly discover you're actually walking on the road back home. (Sirag, from prologue to Wilson, 1977 p. xix & xxii)

Reinterpretation

It is gross understatement to say that the experience of major mental illness is an experience, after which, one will never be quite the same. The crucial question becomes, just what will one be? No matter your theories about etiology or causality, the issue for the human being that has survived the experience is what now?

- I say, reality is unreliable, it loses touch with reality.
- I say, reality is unreliable it can change its rules, and suddenly, without notice, set chaos upon you, like a raging storm jumping up from the depths of the Sea of Galilee.
- The real is something very different from anything you ever told me about!

Here is the ontological crossroads. Here is the taboo. Here is the question our science refuses to answer. From this point on, the subject is on her/his own. Much is directed toward the object the subject has become, but the subject is profoundly alone. We cannot speak, of what is real.

My experiences in the realm of mental illness were immanently real. The strange and bizarre phenomena I lived through were every bit as real as holding my first child minutes after her birth. My experience of mental illness was, as real as feeling the earth under my feet, watching a sunrise.

- Don't tell me about judgment and insight!
- Don't tell me about the validity of my thoughts and feelings if you have never seriously questioned your own certainty regarding your judgments, insights, perceptions and interpretations.

Reinterpretation is a slow arduous struggle. It is developmental, and more often evolutionary than revolutionary. Piece by piece by piece a new self and new reality is painfully constructed, like rebuilding a house out of the rubble left by a tornado.

For sure, aid is given. I have spent years of my life existing as a footnote, a case note, a clinical note, clinging to the understanding that I was a defective biological unit. Somehow time, matter, and the joke of genes and enzymes had exiled me to the sidelines of being. This may truly be a valuable perspective for those who observe mental illness, but for me, as subject, this tree bore only dry and tasteless fruit.

- I have a chemical imbalance it wasn't really me that did those things.
- I have a chemical imbalance I really didn't feel those things.
- I have a chemical imbalance I really didn't experience those things.
- I have a chemical imbalance I didn't really think those things.
- I am a chemical I don't really think. Here is an insight! The entire human drama of love, suffering, ecstasy and joy, just chemistry.
- Oh.. to be a pretty, balanced, buy-oh-chemikal, all drew s seed up with nowhere to go.
- You are just a buy-oh-chemikal too.

Perhaps the ghost in the machine was just too much a poet, a shaman, or plain scientist to settle for the interpretation. Interpretation after interpretation was

slowly constructed. The destruction of each was described as decomposition, as recidivism. Fortunately, there are other songs beside the empty song of materialistic medicine. There are the works of Carl Jung, which my psychiatry professor dismissed as “spiritual”. There are the great mystical traditions of every culture. There is the literature of the “unexplained”.

Most significant, for this person, are the insights of modern physics, and contemporary logic. For this patient, an understanding of Gödel’s theorem is more valuable than all that is known about microanatomy. For this client, an appreciation of Bell’s theory is much more valuable than all that is known about neurotransmitters. For this consumer, to merely speculate in awe, about whatever Carl Jung and Wolfgang Pauli were trying to articulate is more valuable than any hope of having the most perfectly balanced nervous system. Let’s not forget the words of that lighthouse author of the English language. “There are more things in heaven and earth, Horatio, than are dreamt of in your philosophy’ (Shakespeare, 1603/1969 p. 120)

For me, balance means trusting my experience as much as the experience of any expert. For me, balance means trusting my mind as much as medications. For me, recovery was impossible until the mind constructed an interpretation of self and reality that provided judgments that could be trusted and insights about a life worth living.

Return

“I am because we are.”

- African American Affirmation

What is a life worth living? For most humans’ beings, a life worth living is a life of connectedness. Few persons choose to live as hermits. Recovery and reinterpretation, requires return to reciprocal relationships. Return to connectedness with the human family, the larger society, one’s cultural context, family, and friends. This may be the greatest challenge in recovery because of the reciprocal nature of interpretation. So much of what we perceive about ourselves and our environment is dependent on information from other. The more significant the “others” the greater the impact of the signals received from them.

The importance of social or “human ecology” issues in recovery can not be overemphasized. Significantly, the role and affect of social, or human ecology factors, may be very different when viewed within a recovery paradigm as compared with a treatment paradigm. The importance of family to the survival of a person considered mentally ill should be unquestioned. The affects resulting from relationships within the family, can be very different, if the focus of those

relationships is caretaking, and treatment rather than just being a brother, sister, mother, father, or cousin. In theory at least, you can choose your therapist, you cannot choose your family. Certainly I have needed help from my family and friends as a person suffering with mental illness. But as a person, I have needed to be a brother, son, and father much more.

Recovery involves reassociation “To be attached to the subdivisions, to love the little platoon we belong to in society, is the first principle (the germ as it were) of public affections” (Burke, cited in Berger & Neuhaus, 1977, p.4). I suspect that much of the power and effectiveness of self-help and peer support groups stems from the capacity of these groups to meet these basic and essential human needs.

Finally, if we are to consider reassociation into the human social context, we cannot ignore the importance of employment. The vocational aspirations of a survivor of mental illness are at least as important as the vocational aspirations of a corporate executive, budding politician, or third year medical student. Shortly after becoming employed, I remember being profoundly moved by reading a simple statement regarding vocational rehabilitation for persons with mental illness. – “The thing that transforms a patient to a person is a job” (Unknown). Return to the human ecology must be very difficult without active participation in the human economy.” Exclusion from the world of work is, at best, equivalent to exile to the margins of society.

Religo – Religare

There is an aspect of the recovery process that I’ll describe as “making peace”. I suspect “making peace” is important work for survivors of any cataclysm. The experience of major mental illness is certainly an experience after which one will never be same. What will one be? To return to the human family, as a participating, co-creative consciousness is the major work of recovery. To return renewed with an enriched perspective of the human condition is the major benefit of recovery. To return at peace, with yourself, you experience, your world, and you God, is the major joy of recovery.

I believe it is particularly important to pay special attention to issues of spirituality and relationship to the deity when we consider recovery. I cannot believe that anyone who has suffered the kind of disruption to notions of self and reality brought about by mental illness, has not also suffered similar disruptions of notions of spiritual life and deity. I have never known a patient, client, consumer, or survivor who was not deeply involved with matters of spirituality and or relationship to the deity. This is the realm of religion. Reinterpretation of spirituality is the beginning of peace. Redefinition of one’s relationship to deity is the home of peace. Return to a life based on ones’ unique experience of deity is making peace.

WHAT IMPACT WILL RECOVERY HAVE ON YOUR LIFE AND WHAT COPING STRATEGIES HAVE YOU USED IN YOUR RECOVERY?

I hope the answer to the above question is clearly if not explicitly answered in the preceding, rather lengthy, personal description of a recovery model and process. To briefly, and directly address the issues of impact and strategies relevant to a recovery perspective, I will suggest consideration of another metaphor. As an African American youth (actually I was a Black youth at the time) coming up in the heart of Cleveland's Black (or African American) community I was advised numerous times "Don't let your schooling interfere with your education". This proverb is fraught with as much danger as wisdom. I am certain that this saying does not mean that completing one's schooling is unimportant. I am also certain that it does suggest that, becoming educated is more important. My education and my recovery is, ultimately my work, my responsibility. "Don't let your treatment interfere with your recovery." From my experience, any strategies or impact of a recovery perspective derives from the realization and appreciation of the difference between treatment and recovery. I have defined recovery as returning to the status of sentient, co-creative human consciousness, participating in a life worth living. I cannot take responsibility for my genes, my neurophysiology or the current state of the healing arts. I must take responsibility for the quality and the value of the life I live.

Generally, humor and a positive outlook are essential to any difficult undertaking. Respect and appreciation of others are necessary visas for any traveler planning a trip home to the human family. Most importantly, if for some reason, you do not have a mind you can trust, do whatever it takes to create a mind you can trust. Trust it, and use it.

HOW CAN THE MENTAL HEALTH SYSTEM BEST ASSIST YOU IN YOUR RECOVERY PROCESS? - WHAT IMPACT WILL RECOVERY HAVE ON SERVICE DELIVERY? WHAT LEGAL OR ETHICAL ISSUES COULD ARISE AS A RESULT OF THE RECOVERY PARADIGM?

From the social systems perspective (Warren, cited in Granger, 1991) there are five primary functions that a community performs 1.) production and distribution of basic goods and services 2.) socialization 3.) insuring socio-economic participation 4.) maintaining social solidarity and 5.) controlling behaviors. Currently there is a disturbing lack of clarity regarding the role of the mental health system in society's response to the problem of mental illness.

The mental health system could go a long way in assisting my recovery process by being clearer in making distinctions when it is attempting meet these different social needs. I can accept that the mental health system has a responsibility to the larger society to insure that my behavior is within certain limits. I cannot accept that the focus of my treatment should be the most expedient, cost

effective, measures to make me acceptable in anyone's sight. I may not want or need to be acceptable in your sight. What I want and need, is access to a life worth living. I may need help understanding society's limits. I certainly want access to the best therapeutics available. But I do not need the confusion of believing that my wellness, mental health, or wholeness as a human being depends, in any way, on diagnostic categories. I may walk down the street carting on a lively conversation with myself. People may stare and cross the street. Is that beyond the limits in the land of life, liberty and the pursuit of happiness? If not, the concern is how my "illness" interferes with my access to a life worth living.

The source of this lack of clarity goes well beyond the structure of the mental health system. It involves our legal system and deep cultural belief about persons who are considered to be mentally ill. My dream mental health system would insure voluntary and universal access to the most effective therapeutics, as established by the most advanced scientific methodologies. This dream system would provide leadership to all social structures involved with socialization, including the media. My ideal mental health system would compassionately attempt to insure that the behavior of persons considered mentally ill is within the same well defined limits codified for other citizens. Most importantly this system would be a formidable advocate and watchdog upon our other social structures, seeking to insure equitable access to social and economic participation for its constituents, and vigilantly protecting those God given, inalienable rights, to life liberty and the pursuit of happiness.

RECOVERY FROM AN AFRICAN AMERICAN PERSPECTIVE

The issues of coping with, and surviving multiple and compounded oppression should be obvious. I am reasonably certain, that as young, mentally ill, black male I endured a disproportionate number of "inappropriate" violent police arrest and transport to mental health facilities. I also firmly believe that as a result of my demographic characteristics, I repeatedly received useless and destructive diagnosis of my psychiatric condition. It was not until my inpatient care moved from the middle class medical center to the local state hospital that the interference of arrogant racist assumptions was minimized in the therapeutic process. These kinds of issues and problem resulting from our racist cultural heritage should come as a surprise to very few.

What is more interesting to me regarding recovery from an African American perspective, is the striking parallel in the coping strategies and mind sets useful for surviving mental illness, as well as life in white America. The language and issues of Africentrism, and consumer empowerment is remarkably similar. Kujichagulia – self determination symbolized in the struggle for the right to name ourselves. Just when you're comfortable with client and Negro, we will demand to name ourselves black and consumer. Become comfortable with consumer

and black and our need is to demand that we are African Americans and survivors. The language is revealing another struggle. The struggle for agency – the right to be actor not just acted upon in the dominate construction of reality. The right to assert the reality of our experience, our perspective.

- Columbus discovered America!
- Right from your perspective, but what does that say to the Iroquois?
- My reality is a chemical imbalance!
- O.K for you, but I am much more than chemistry.
- Euclid is the father of geometry!
- Sure but what an I going to tell my sons about how the pyramids got here?

Every experience is valid. Cultural structures that have the effect t of invalidating anyone’s experience does violence to us all. To be sure, having had twenty some years experience, surviving white America gave me some preparation for surviving the destruction of mental illness just when they need all their resources just to survive America. I am grateful for all my experiences, so make no mistake, just as the musician-poet said: “I’m not better, just better sweet.” -- Rhashan Roland Kirk

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The Wounded Prophet

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THE WOUNDED PROPHET

by Sally Clay

ABSTRACT

Recovery Dialogues fail to address the nature of mental illness. The author describes her years of experience with psychosis, and her spiritual journey of recovery.

In the past, altered states were valued in the shamanistic/leadership way. Meaningful treatment for mental illness needs to recognize psychosis as an altered state.

Two spiritual practices-wisdom and compassion-are prescriptions for mental wellness in general. Mental health professionals should study the dimensions of consciousness, and be trained in compassion and wisdom.

Sanity can co-exist with "symptoms." When Jacob wrestled with the angel, he was wounded, a sign that he had "struggled with God and with men and overcome."

Overcoming is suggested as a better goal than recovery.

Moses said to the Lord, "O Lord, I have never been eloquent, neither in the past nor since you have spoken to your servant. I am slow of speech and tongue."
(Exodus 4:10)

Moses stuttered. His disability remained even after he had been to the mountain top and returned with the authority to lead his people. It is why his brother Aaron had to act as his spokesperson. Moses never recovered.

Recovery is the latest buzz word in the mental health field. For the last year or so, I have been labeled "recovered from mental illness." I acquired this label when the Office of Mental Health in New York State invited me to participate in their Recovery Dialogues. I was one of a select group of consumer/survivors chosen to discuss the concept of recovery with a group of psychiatrists.

These dialogues are ongoing, and they have been very interesting. We have covered a wide range of topics, from complaints about mental health treatment more damaging than healing; to consumer participation in the education of

psychiatrists; to personal descriptions of madness; to coping techniques and the management of symptoms.

What the discussions have failed to address, however, is the nature of mental illness itself. Several of us in the “recovered” category have described our extreme mental states in the hope that these might inspire examination of what really happens in the mind, as well as the body, of the person labeled mental ill. If we are recovered, what is it that we have recovered from? If we are well now and were sick before, what is it that we have recovered to? For some reason this discussion never gets off the ground. The psychiatrists in our dialogue become visibly uneasy when the subject arises, and they divert the discussion to a less threatening line of thought. “Coping mechanisms” are just such a diversion, an attempt to regard the depth of madness as something that can be simply “coped” with.

It only makes sense that, if we are “ill,” then this illness must have an objective marker. Diabetes, for example, is identified by a blood test that reveals a deficiency of insulin. AIDS is identified by a virus in the bloodstream. Cancer is identified by a tumorous growth visible in x-rays. But mental illness has as yet no objective marker. Although it is widely speculated that brain chemistry is the culprit, there is no laboratory test that will reveal the biochemical nature of our illness, or even whether or not we are ill at all. Genetic markers for manic depression have been announced, and then found to be mistaken. The truth is that the current state of the art for psychiatric diagnosis is based solely on the subjective observation of external behavior-not a very objective marker for a process that is internal.

Those of us who have had the experience called “mental illness” know in our hearts that something profound is missing in these diagnoses. They do not take into account what we have actually endured. Even if the “bad” chemical or the “defective” gene is someday found, madness has its own reality that demands attention.

There is something compelling about the experience of an altered state, something the Ed Podvoll calls “The Seduction of madness” (Podvoll, 1990).

What is compelling about madness is the tantalizing hint that it holds the secrets of consciousness, of healing, and of spiritual power. It is madness that brings the mind to our attention, that makes us remember that mind is inseparable from spirit, that it is consciousness that makes us human> A great Buddhist lama once wrote:

Spirituality, self-existing, radiant,
In which there is no memory to upset you
Cannot be called a thing.
(TILOPA, 1963)

For me, becoming “mentally ill” was always a spiritual crisis, and finding a spiritual model of recovery was a question of life or death. My search began over 30 years ago, when I took time off from college studies to shut myself in my room alone to find God and the meaning of life. For a week or so, I listened to music, entertained myself with mental images, and had spiritual revelations. I experienced many unusual perceptions and bodily changes similar to ones that occur with drugs such as LSD. All of this climaxed with a vision of the oneness and interdependence of everything in the universe-the sort of thing that sounds foolish when put into words, but is profoundly true for those who experience it.

But my extreme mental state did not wear off the way drugs eventually do. After a while my mood turned ugly and destructive-like a “bad trip” that would not end. I struck the school nurse, breaking her arm, and I plunged into a hell of darkness and despair. When I did not eat or sleep or talk to my friends, the college called an ambulance to pick me up. The attendants gave me a shot of Thorazine, put me into a strait jacket, and carried me off. At the mental hospital I was diagnosed with schizophrenia, locked in seclusion for several weeks, and drugged with 1200 mg. a day of Thorazine. Later the doctor told me that my entire experience with spiritual ecstasy and darkness was sick and irrational, and had no meaning whatsoever. Shamed, I stayed in the hospital for five months, and by the time I got out I was a sadly different person from the one who had seen God just a few months before. I was defeated. I considered myself a complete and utter failure for the rest of my life. God was gone.

I was not allowed to return to college, and most of the people who had been my friends would no longer talk to me. I felt so weak and degraded that I could not work, and I enrolled in secretarial school only because my mother insisted. After a year I was well enough to get married and find a job. I did well on the job, but after six months I suddenly cracked up again and wound up back in the hospital. Since then I have been hospitalized over 18 times, once for as long as two years.

I have been given just about every psychiatric drug in the med room-major tranquilizers, minor tranquilizers, anti-depressants, mood elevators, sleeping pills, lithium, and Prozac. I have spent more days in seclusion rooms that I can count, and I have been tied down in five point restraints, I have received both insulin shock and electric shock. Few of these “treatments” helped me at all, and most of them damaged me badly. They left me debilitated and desperate. One might wonder why I am still standing at all. I certainly owe no thanks to the mental health system. The faith in my inner experience always returned to strengthen me; it is only this spiritual outlook that enabled me to go on.

As a child I had loved the silent time before the liturgy began at church. I would kneel on the prayer bench for a long time, absorbed in silence. In high school, without giving a name to what I did, I often sat alone in my room or outside in the mountains or woods, and I learned to trust the peace and confidence that this brought. Oddly enough, I did not realize how precious this was, for at the time it

was simply a part of whom I was and what I liked to do. Spirituality is like that-it is so close to you that it may not seem very important. Because I had faith in my mind, and trusted it, I never lost touch with fundamental reality, even when later I became depressed or manic or fearful. Whether my thought became threatening or blissful, I knew that behind them all was spiritual stillness. I knew that although my emotions may arise from brain chemicals, or may themselves trigger chemical changes, the form my emotions take and the meaning I give them are my responsibility.

Even after the horrible treatment that I received in every single one of the mental hospitals, secretly I cherished the spiritual vision of my altered states. That could not be erased, because it was real. Even when depression and despair followed a manic episode, my vision of truth prevailed over the sorry platitudes and euphemisms offered as help by friends and therapists. Those lies were never real in the way that my vision was. Nevertheless, for fifteen years I lived a lie. I tried to regard my spiritual experiences as symptoms of illness, and dutifully kept my life safe and dull and meaningless. It never worked. Inevitably my mind would go its own way, and I would once again wind up in a mental institution.

My healing did not begin until 1978, fifteen years after my first hospitalization. I began to study and practice Buddhism, where I found a comprehensive psychology of the mind and specific methods to overcome confusion and suffering. I found descriptions of mental states identical to those I had experienced when "mentally ill." Most of all, I found psychology presented as part of a spiritual process, a psychology of the heart (Freemantle, 1975; Govinda, 1969; Trungpa, 1972). Finally I could admit openly that my experiences were, and always had been, a spiritual journey-not sick, shameful, or evil. I was already a worthwhile person, right from the start, and there was a way to work with my own mind to transform fearful mental states to peaceful ones.

Of course nothing is as simple as that. I found at first that sitting on a meditation cushion in Buddhist fashion was very difficult to do when my mind was disturbed. I could not keep up with the people who meditated for hours at a time at the centers I attended. Finally I spoke about this to a Tibetan lama in Woodstock, New York, and I honestly admitted my diagnosis of mental illness. With trepidation, I confessed my conviction that I gained precious spiritual insights from my experiences. Unlike Western friends and therapists, he did not try to convince me that my spiritual concerns were trivial and just another symptom of mental illness. He took what I said seriously, and his advice was that I bring my understanding into the community, and use it to help others.

That is how I began working as a peer advocate and counselor. After my talk with the lama, I first volunteered for the Red Cross in Portland, Maine, and worked on their disaster team. Then I found a small group of psychiatric survivors and organized the Portland Coalition for the Psychiatrically Labeled. Little by little I learned how to give peer support to other people, and how to

advocate for them within the mental health system. The more I did this work, the more confidence I gained in myself. For the first time since college, I started to feel like a real person, somebody worthy of respect. Not only that, I began to receive respect, not just from other ex-patients, but also from people in the community.

As I gained in confidence and in the practice of compassion, I found it easier to practice the mental disciplines I had been thought. I began doing meditation for 20 minutes a day and I also went back to church and joined the choir, for I have always enjoyed singing. Still, I kept “going off the deep end” and had to be re-hospitalized almost on a yearly basis. Weary of battling these psychotic episodes, and overstressed by my work, in 1988 I returned to Woodstock and took an apartment near the Tibetan monastery. I hoped that spiritual practice would help me clear away anger and fear, the emotions that caused my mental states to get out of control. My teacher, Khenpo Karthar Rinpoche, gave me individual instructions. I was assigned the practice of the Green Tara Sadhana, a chanting meditation in praise of Tara, a female deity of compassion and wisdom (Willson, 1986). For two years, I practiced intensively at KTD Monastery, and I heard oral teachings from many high Tibetan lamas. Hearing the teachings confirmed to me that my spiritual interpretation of manic experiences was valid, and my insights were genuine.

After this period, I again ventured out into the world. I volunteered at a local 24-hour community hotline, and joined peer support groups in two nearby towns. Within a couple of years I organized the support groups into a non-profit corporation called PEOPLE: Projects to Empower and Organize the Psychiatrically Labeled. Modeled after the Portland Coalition, PEOPLE became a force for advocacy and a resource for support throughout the Hudson Valley in New York.

It has now been eight years since I have been committed to a mental institution. Although I cannot claim stability in my life, much less enlightenment, my anger and fear are greatly reduced, and my impulses no longer drive me over the edge into madness. More than ever, I am convinced that this recovery, if you can call it that, is the result of my spiritual practice. The faith that I learned long ago from silent prayer made it easier for me to understand my mental states without fear. The green Tara Sadhana, a kind of yoga, allowed me to stabilize my mental state by integrating mind and body. The help that I have given other people taught me compassion.

But I must also give a certain amount of credit to my madness itself. When I came to study at the monastery and listened to the high lamas, I compared what I heard to what I had experienced. It all fit together. Everything that the lamas taught about the nature of the mind coincided with what I had already learned within my altered states of consciousness. From the lamas I learned how very

important it is that we respect our consciousness, in all its dimensions. It is a house of many mansions.

The questions remain. If mental illness is a disease of the mind, what is the nature of the mind? If altered states have value, what is there to recover from? What is our model of wellness? Is it true, as some say, that spiritual realization is the highest aspiration of the human race? If it is, should not that be our model of wellness? How do we recover to that state of wellness? Is recovery for a mental patient something different from the wellness of any other person?

Why do people in mania consistently experience an urgent call to save the world, and call themselves messiah or savior? Is this merely grandiose, or do such people truly hear a call to help other?

We know that people called schizophrenic hear voices. But why do they listen to them? Why in this culture are some forms of mental illness so excruciatingly painful and so interminable? Is illness the reason, or is there a tragic misunderstanding of global proportions? Who is ill-is it the visionary or is it the society itself?

We now know that mental illness appears in a very high proportion of creative artists and world leaders. Some persons who achieved greatness in spite of-or even because of-mental affliction are the artist Vincent Van Gogh, poet Robert Lowell, and President Abraham Lincoln. Is this a fluke, or is there actually an indispensable link between madness and creativity?

For centuries, ever since human beings emerged distinct from apes in the chain of evolution, people have experienced extreme mental states. In most societies, altered states of mind have held a place of respect, and have served to give spiritual meaning to the culture. In indigenous cultures, for example, the shamanistic tradition involves an individual's journey through his or her own mind. This journey is typically painful and even turbulent, but because the people who experience it are guided through it by spiritual elders and the community itself, they emerge from their ordeal with newfound wisdom and the power to heal.

Eastern peoples believe that mental disturbance is a question of both body and soul. Although emotions come from the brain, the mind is located in the heart, not the head. Mind and heart are synonymous. Thus the brain is part of the body, but the mind is part of the spirit. In the ancient Hindu scripture, the Bhagavad-Gita, called the "Song of God", it says: "One must elevate oneself by one's own mind, not degrade oneself. The mind is the friend of the human soul, and its enemy as well" (Murray, 1980). In ancient Tibetan medicine, madness was considered the easiest of all maladies to cure, and it was treated with the

use of herbs, diet, and spiritual practices (Clifford, 1984). Buddhism, like other contemplative traditions, uses the discipline of meditation to open up dimensions of extra-ordinary mental states that lead to spiritual wellness.

Even the Judeo-Christian religions are founded upon the inner experience of the heart. When Moses went up to the mountain, he experienced an altered state of mind. He had a vision -you might say hallucination-of a burning bush, and a face to face encounter with something for which he had no name, and which terrified him.

There the angel of the Lord appeared to him in flames of fire from within a bush. Moses saw that though the bush was on fire it did not burn up. So Moses thought, I will go over and see this strange sight-why the bush does not burn up."

When the Lord saw that he had gone over to look, God called to him from within the bushes, "Moses, Moses!"

And Moses said, "Here I am"

[Yahweh told Moses that he was being sent to bring the Israelites out of Egypt]

Moses said to Yahweh, "Suppose I go to the Israelites and say to them, "The God of your fathers has sent me to you, and they ask me, "What is His name?" Then what shall I tell them?"

God said to Moses, "I am is that I am. This is what you are to say to the Israelites: I AM has sent me to you."

(EXODUS 3:2-14)

It was this experience that made Moses a prophet. Later, of course, he received the Ten Commandments and brought the stone tablets to his people. But that was later. The experience that enabled Moses to lead his people to the Promised Land was an altered state of consciousness. And many of us who have been labeled mentally ill know first hand what that altered state is like.

We know what the "I am" is. If we are Buddhists we know what "such ness" is. If we are shamans, we know who we are.

Until recent times, altered states of the kind I have described were an integral and integrated-part of human experience. Among the ways they were incorporated into society were the shamanistic/healing way, the contemplative/teaching way, and the prophetic/leadership way. It is only recently that altered states have been medicalized and stigmatized. It is only recently that powerful drugs have been used to suppress the altered states that once produced our prophets and our saints.

Not surprisingly, it is also recently that society has fallen into a spiritual crisis of unprecedented proportions. In case you had not noticed, we no longer have any shamans or prophets. There may be those who go by those names, but somehow the mental experience that shapes such people is missing. This lack is sorely felt. We are lost now, lost on a global scale. Our world has lost its meaning, and our religions have lost their authority.

Not surprisingly, millions of people today are seeking to reach an altered state in the only way that they know how-through the use of mind-altering drugs. We may try with all our might to get rid of the drugs, but as long as we are human, we will not get rid of the need for altered states.

Buddhism identifies two components of spiritual realization-wisdom and compassion. It prescribes meditation to attain mental clarity and good works to learn Compassion. The intimate experience of mind through meditation opens the heart to compassion. Similarly, the good that we do for ourselves and others opens our minds to wisdom. The *Bhagavad-Gita* says, "One whose mind is controlled and who strives by right means is assured of success" (Murray, 1980). And Jesus was talking about the same two activities when he named the two great commandments (Matthew 22:37-39). The first is to "love the Lord your God with all your heart and with all your soul and with your entire mind." This corresponds to wisdom. The second great commandment is to "love your neighbor as yourself" – and this is the same as compassion.

For me, Dharma practice was healing, for I found that the two Buddhist aspects of enlightenment-wisdom and compassion-are prescriptions for mental wellness in general. By following them, I achieved what others have called "recovery." But clarity and love are not restricted to Eastern religions, and we need not turn to esoteric practices to find a cure for mental suffering. We do, however, need to reexamine mental health treatment from the perspective of mental states-in other words consciousness. I believe that any meaningful treatment for mental illness must have a spiritual basis.

Any model of healing the mind must begin by acknowledging the spiritual properties inherent in altered states. It will include a human exchange between client and provider, one in which the client can share and even transmit what he or she has learned. People who have experienced madness have something to give back to the world. It is no coincidence that we are likely to be sensitive thinkers, talented in the arts, and understanding of others. Many of us have seen the "I am," have understood the "such ness" of phenomena, and want to help others.

Mental confusion may need medical technology, and even drugs, to help them "cope." But any good psychiatrist, psychologist, or mental health worker must first be a decent human being-and certifies as such!

When we talk about finding a "cure" for mental illness, it is important to expand the definition of sanity to include clarity and compassion that co-exist within so-called "symptoms." Health, or sanity, can be achieved even within an affliction or disability. As examples, both Franklin Delano Roosevelt and Helen Keller were severely physically disabled, yet one became the leader and the other the

teacher of millions of people. In my case, the healing process and my successful work as a peer advocate stated while I was still suffering periodic breakdowns, and continued for some time while I was still going in and out of the hospital.

Few of us who have been psychiatrically labeled would claim to have recovered to the point where we no longer experience our manic energy, our depression, our choices, or even our confusion. It is embarrassing, but I must admit that for the last six months I have been quite depressed myself. I do not think I will ever again get so out of control that I will have to be hospitalized. But even if that should happen, I will not lose faith in my experience and my journey. I take comfort in another lesson that I learned from the Tibetan lamas. These holy people, and holy people I have met in other traditions, are remarkable for their very humanness. They have quirks and foibles and frailties, but these in no way contradict their spiritual realization.

Often ex-patients and patients within the community are expected to endure lives like those we see all around us. Everywhere these days we see people living lives of quiet desperation-lives, as Kierkegaard noted, of 'indifference,...so remote from the good that they are almost too spiritless to be called sin, yes almost too spiritless to be called despair.' (Kierkegaard, 1954). We who have experienced mental illness have all learned the same thing, whether our extreme mental states were inspiring or frightening. We know that we have reached the bare bones of spirit and of what it means to be human. Whatever our suffering, we know that we do not want to become automatons, or to wear the false façade that others adopt.

Whether we have had revelations or have hit rock bottom, most of us have also suffered from the ignorance of those who fear to look at what we have seen, who always try to change the subject. Although we have been broken, we have tasted the morrow of reality. There is something to be learned here about the mystery of living itself, something important both to those who have suffered and those who seek to help us. We must teach each other.

We must teach each other, knowing that it is often the wounded healer, or the wounded prophet, who is most able to help others. The stigma that we bear need not be a mark of shame. Instead, like Jacob after he wrestled with the angel, we can wear our disability as a badge of honor. In Jacob's first altered state, he received a wound that stayed with him for the rest of his life:

That night..., after Jacob had sent his family across the stream, he sent over all his possessions. So {he} was left alone, and a man wrestled with him until daybreak. When the man saw that he could not overpower him, he touched the socket of Jacob's hip So that his hip was wrenched as he wrestled with the man. Then the man said, "Let me Go, for it is daybreak."
But Jacob replied, "I will not let you go unless you bless me."
The man asked him, "What is your name?"
"Jacob," he answered
Then the man said, "Your name will no longer be Jacob, but Israel, because you have Struggled with God and with men and overcomes." (GENESIS 32:22-28)

Jacob named the place of his struggle Peniel, which means "face of God." I, too, have seen God face to face, and I want to remember my Peniel. I really do not want to be called recovered. From the experience of madness I received a wound that changed my life. It enabled me to help others and to know myself. I am proud that I have struggled with God and with the mental health system.

I have not recovered. I have overcome.

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Report**

RECOVERY INSTITUTE

On September 29-30, 1994, the Office of Mental Health convened a Recovery Institute, a forum on recovery for persons with mental illness. The participants of this institute comprised Chief Executive Officers (CEO) and Medical Directors of the state mental health hospitals, Office of Mental Health top management staff, and a small number of agency staff. Eight presenters discussed recovery from the consumer, family and professional perspectives. As part of their presentation, presenters were asked to respond to the following questions:

1. What is the recovery paradigm?
2. What impact will/does recovery have on your life and what coping strategies have you used in your recovery?
3. How can the mental health system best assist you in your recovery?
4. What impact will recovery have on service delivery?
5. What legal or ethical issues could arise as a result of the recovery paradigm?
6. How can clinicians integrate the concepts and process of recovery into treatment?
7. What does the mental health system need to do to shift thinking and services toward a recovery philosophy?
8. How can families support the recovery process for their family member and what skills are needed?

All of the presenters did an excellent job of explaining the recovery process. Presentations were followed by some very good and meaningful dialogue between the presenters and the participants who reinforced and added to the learning environment.

EMERGING THEMES

The major themes that surfaced from the presentation and dialogue were:

1. “Allowing wisdom to be” – mental health professionals must learn to listen to what the consumer is saying and to respect that there is many times a certain wisdom that comes with the illness;

2. Spirituality - a strong sense of spirituality was important to all the presenters;
3. A sense of and the need to belong to a culture and society;
4. The wisdom of self, the internal world as well as the external world;
5. The wisdom and need for love/relationship between human beings;
6. Everyone has their own path, so we cannot use the same map to direct people;
7. We cannot lead nor follow someone in their recovery, we can, however, be the tool to assist them in their recovery;
8. We can and should create “an environment for recovery.”

RECOVERY ENVIRONMENT

An environment for recovery as outlined by Ms. Amy Long in her presentation is one that has the following components:

- A. Everyone (consumers and staff) would be treated with dignity and respect
- B. There would always be a sense of HOPE
- C. There would be open doors
- D. There would be freedom of choice and options
- E. Medication would be an option not a given
- F. It would be a place where medication is not the only answer - and there are many options
- G. Symptoms would be tolerated and understood
- H. Internal controls would be valued and promoted
- I. There would be support for a sense of spirituality
- J. There would be an environment of safety
- K. Honesty would be valued and promoted
- L. There would be the opportunity to have work as an option

ADVANCE DIRECTIVES

Another presenter educated the participants about advance directives. He skillfully described and explained his illness. He then read the document that he had designated as his Advance Directive. He had thoughtfully conceived and

written down what he wanted and how he wanted to be treated in the event of a mental health emergency or crisis.

SYSTEM QUESTIONS

The two presenters highlighted above are mentioned because they both gave very concrete knowledge that can be shared and implemented at the system's level with little difficulty. As well, dialogue between these and the other presenters and participants resulted in some very hard questions:

1. If not forced medication then what should be the next steps when working with individuals who refuse medication,
2. Is it possible to motivate very low functioning consumers and give them a sense of hope,
3. Can and should a clinician have shared responsibility and power with a consumer during their illness,
 - The dialogue surrounding this particular question led to an interesting discussion on the power of psychiatrists, its impact on consumers and family members and how they should respect and utilize that power; As one presenter stated "you have the power to take away one's autonomy but how and when do you re store that autonomy back to the individual, also when and how do you communicate to the individual the decision to restore."

AREA OF CONCERN

An area of concern mention several times throughout the two days was the frustration of the staff. This is a concern that should be dealt with separately, however, it should be understood that if staff are frustrated it will probably be harder for them to incorporate and internalize the changes necessary to develop a recovery environment (mainly because it is a change). The mental health system must come up with some type of reward mechanism for staff to help offset the impact of stressors and frustrations they encounter.

NEXT STEPS

The presentations and presenter – participant dialogues identified the following as next steps toward the development of a recovery environment within the mental health system:

1. To duplicate the institute/forum for all mental health staff and consumers;

2. Forums should include a cross section of parents, consumers and professionals, as well as children's people, setting at the table;
3. To promote "Hope" as a key component of recovery through the building of relationships between consumers and professionals by promoting "consumers and professionals as partners";
4. Do an analysis of the recovery concepts; prioritized them and decide on means of implementation;
5. Include faculty and students from universities;
6. Encourage patient populations to embrace the recovery model and to provide education regarding recovery;
7. Develop and promote "peer support" within "our" (hospital, agency, community) settings; and
8. Distribute booklets to everyone.

SUMMARY

The Recovery Institute provided the forum where consumers, families, and professionals could begin to address mental illness issues from a different perspective. The positive dialogue between the presenters and participants identifying a number of common themes of recovery, as well as the steps the system will need to take to begin to incorporate and promote "recovery" as a value of the Louisiana Office of Mental Health and the consumers and families for which it provides services. This Institute was only the first in a series of dialogues and activities which the mental health professionals of Louisiana in partnership with consumers and families must participate in order to incorporate and promote the recovery process.

David Collier
Louisiana Recovery Forum

RECOVERY

Recovery is the new buzz word in mental health circles. It suggests hope, optimism and a brighter future. The old buzz work coping suggest a “settling for the way things are.” We have other buzz words to build on. Such as Alternatives, Empowerment, Journey, Adventure and Network. I will start by talking about recovery from mental illness. Mental illness is a very personal experience. The symptoms and sufferings associated with mental illness are as varied as are the inhabitants of the earth. Each individual’s experience with mental illness is unique to that individual. To classify someone as schizophrenic, manic depressive or neurotic only gives you one narrow view of the person. Each mentally ill person is much more than his or her diagnostic label.

Because of the uniqueness of each individual’s experience with mental illness each individual’s recovery is also unique. I will talk of my recovery and myself, because I know more about myself and my own experiences. Doctors write books about mental illness and describe their observations and make conclusions. However, to really understand the experience one has to live through it. One could argue that a doctor knows more about heart disease than the patient who experiences it. However, heart disease is a physical problem. Mental illness may have its basis in the chemistry of the brain but it is only diagnosable as behavior deviating from the norms of the individual’s culture. In fact doctors sometimes have a distorted view of the patient because of the very diagnostic labels that have been developed to give more precision and clarity to our understanding of mental illness.

As I said the diagnostic label only gives a narrow view of certain aspects of a mental health consumer’s personality. I know from my own experience that doctors frequently have inaccurate views about the patient’s potential to recover and function in society. Many times we have heard the story of the “basket case” for which the doctors held little hope for substantial recovery. Some of these people go on to write books about their experiences and contribute profound wisdom to our society.

I will speak of my own sufferings and recovery in the hopes that others may find some useful ideas from it. Tales of personal torture can be like pornography- evocative and exciting when first heard, yet after a while they become boring, dull and downright disgusting. However, these tales of woe are necessary because without them their world be no revelation by which to compare the recovered personality.

Thirty five miles northwest of Baton Rouge is one of the most beautiful fishing and recreational boating areas in Louisiana. Thousands of years ago the currents of the mighty Mississippi River decided to change its course and seek a more direct route to the Gulf of Mexico. This natural occurrence of mother nature

left behind the setting of what would become to me a natural and inevitable break that I would have with reality.

If the gods were kind enough to allow you to choose a time and place to loose your mind, you could not choose a more perfect setting. On this clear summer day, clouds plucked from the surrounding cotton fields to soak up the humidity clustered over the false river. A river that became impotent when the mother river changed her course.

My friend, brother-in-law, and myself, fished for perch off one of the many rickety old piers that surround False River. To me fishing with a cane pole is the only way to fish. Sit back, let your mind wander and gaze in semi-consciousness at the red and white bobber as it hops across the ripples of water.

On this day I was feeling an incredible kinship with God. The wind, clouds and waters seemed to respond to my innermost thoughts. I helped my companions catch fish. I was convinced that my thinking caused the fish to bite, the clouds to swirl and the wind to blow. Confirmation of God bestowing this unusual gift upon me came when I turned on the car radio and “understood” that the songs that I heard were special messages for my ears only.

In spite of the fact that I had such an obvious break with reality I have never thought of myself as ill, sick or diseased. That is hard to do in light of the evidence otherwise.

I have had the opportunity to read the reports of my bazaar behavior written up by psychiatrist, psychologist and social workers. In my estimation they did an excellent job of recording and analyzing my condition when I went over the edge. Yet I continue to find that basically I am an OK person. I continue to think that there is nothing unnatural about what I have gone through.

Is this denial? Maybe. But think about what the opposite of denial is. Its acceptance. Do I accept being bi-polar, depressed, manic, Schizophrenic? No. If I accepted all these labels I would be defeated before I started. No one wants to accept this kind of assessment. The assessment that I do accept is one of my own choosing. Interesting, intelligent, talented, charming-I will take those labels. God bless the child that resists any attempt to categorize and label his behavior.

My mother did her part to help me recover. Not once did she ever say in the course of my illness that their was ever anything unnatural or sick about my behavior. Did she think it? Possibly. But what happened with me was as natural as the Mississippi River changing course and plunging toward the Gulf of Mexico.

I do think that genetics has an impact on mental functioning. I also think that environment, and family history has a lot to do with what I have experienced. I

grew up with a lot of hostility between my mother and father. They did a lot of drinking, fighting, yelling and screaming at each other.

I reported to my mother one time that I heard voices. She asked me what they said. I told her that I could hear her and my father arguing about me. She indicated that given the nature and severity of the arguments between her and my father it seems natural that this would be the subject of the voices that I heard.

As a result of this, some of the fear subsided about hearing these voices and I began to listen to them in a different way. I started to decode and analyze them to have a better understanding of what is going on in my sub-conscious. I use them as a means to improve myself by delving into my psyche.

It is commonly thought that a person never completely recovers from chronic mental illness. He or she only learns better ways to cope with the attitudes of the larger society toward his or her behavior. A person can and often does learn to express himself in ways deemed more appropriate by larger society. I believe that there are people that completely recover. A recovered person maintains their individuality rather than attempting to conform. A recovered person realizes that in spite of his or her deviance from the norm there is nothing un-natural or bad about him or her as a human being. A recovered person turns a disadvantage into an advantage or as the adage goes "makes lemonade out of lemons".

We can utilize the creativity and unique point of view that frequently comes from seeing the world in a different way than the mainstream. By expressing my point of view in a way that the larger culture can understand. I am able to help others understand mental illness in a different light. This ability to relate in a way that the mainstream can appreciate frequently comes after years of interacting with others in a somewhat impaired manner.

What impact has recovery had on you? First I want to start out by telling you when my recovery began.

Two and one half years ago before I joined the consumer movement I had very little direction and purpose in life. I was in and out of the hospital ascending and descending into my own personal hell. My sense of self worth was practically nil.

For me the consumer movement started before I know one even existed. I was hospitalized at Greenwell Springs Hospital right after the no smoking regulations came into effect. The patients that smoked did everything they could to feed their nicotine addiction. We would smuggle, bribe, steal and chew nicotine gum prescribed by the doctors. One afternoon at coffee time, when the addiction really flares up, a near riot broke out. Everyone was yelling, screaming and banging on the walls demanding a cigarette.

The hospital administrator was summonsed to the ward to see what could be done to alleviate the problem. I was elected to represent the patients and present the Administration with a petition. I went into a board room full of doctors, nurses and staff to state our case. I surprised myself at how lucid and coherent I was as I explained to them that the patients were being taken advantage of by the psych aids. We were paying up to \$5.00 for 3 cigarettes and were left to figure out a way to light them ourselves. I pointed out the fire hazard that was created as we would short out electrical outlets to create a spark to light our cigarettes, not to mention the smoking that would take place in the bedrooms late at night. I also pointed out that the staff had a place to smoke and the patients did not. This was blatant discrimination. I was quite surprised and had my first taste of empowerment when I received a letter from the administrator shortly after my release. She sent me a copy of the regulations that stated that provisions shall be made to accommodate patients that smoke. A smoking area was designated and regular smoke breaks are now routine at this hospital. It is coincidental, but now I work for this administrator at the Baton Rouge Mental Health Clinic. We frequently chit-chat in front of the building as we smoke cigarettes together.

How can the mental health system best assist you in you recovery? I can best answer this question by reading to you a letter that I have written to be placed in my file and given to people that I may encounter in the event that I have another crisis. (Attachment)

I believe the mental health system can best serve the consumer by treating his as a human being not as a mental patient. Too often doctors assume a paternalistic role with the consumer. The best way to help a consumer through recovery is to allow him or her autonomy. To make decisions for the person and assume control over managing their affairs may help the person's immediate problems but in the long run it teaches them to be dependent on the system. A mental health consumer is best served by a system which acts in a supportive role while allowing the consumer to decide what is best for his or herself. The consumer knows best what he or she needs. Each individual must discover what is good or bad for him or her self. Each person must determine their own values. There is no right way to live. Each person must be allowed to make their own choices in their life, whether they live in a group home, hospital or in the community. It is only through making our own choices that we grow and reach our potential. The most fundamental human right is the right to make mistakes.

What impact will recovery have on service delivery? The desired impact is to have a reduction in the demand for services. The following is from a book by Sheldon B. Kipp,

If You Meet the Buddha on the Road Kill Him.

No meaning that comes from outside of ourselves is real. The Buddha hood of each of us has already been obtained. We need only recognize it. Thus the Zen master warns his disciple: "If you meet the Buddha on the Road, Kill him."

The most important things that each man must learn no one else can teach him. Once he accepts this disappointment, he will be able to stop depending on the therapist, the guru who turns out to be just another struggling human being."

When consumers start recovering and begin to realize that their fate lies in their own hands, they will become more involved in self-help. I think that the mental health system that watches this trend and does what it can to facilitate it will flourish.

What legal or ethical issues could arise as a result of the recovery paradigm? Many times ethics and legality have very little to do with each other. Is it right to jolt a persons brain with electricity without their having any say so about it? I think not, but legally it can be done. Is it right to force medication on an unwilling patient? Is it right to medicate people into being compliant? They may be easier to control and cause less trouble, but the ethical and legal concrescences are enormous.

The laws as they are now constituted regarding mental health consumers need reform. Basically the consumer's role in society is hindered more than helped because of the way that mental illness is viewed. When consumers recover they should be seen as individuals who although deviating from the norm have the same inalienable rights as the people of the mainstream.

The implications of viewing the consumer, not as pathological, but as a person whose unique perspective may give us the opportunity to learn and develop our potential are great. Rather than isolating the sick person in a hospital we could allow and encourage the person to participate in the society at large. In Nigeria they have developed mental hospitals where patients still participate in the cultural activities of the outside community.

The laws regarding forced medication need changing. The decision about whether or not to ingest some foreign substance into the body which has known side effects is a very personal decision. It is a decision based on the values of the individual. The doctor may value the beneficial effects of the medicine over the possible harmful side effects, however it is the patient's body and the patient has the right to determine his own values with regard to medication.

I will conclude by reading a letter that I sent to Dr. Zentner, a respected psychiatrist that practices in Monroe, La. (Attachment)

PRE-CRISIS TREATMENT REQUEST

October 19, 1993

TO WHOM IT MAY CONCERN

I am writing these instructions, while I am of sound mind, to have some input into the care or punishment that I may receive as a result of my illness. The most current diagnosis that I have received is that of having a schizo-affective disorder. I have never inflicted harm to anyone else and any harm that I may have attempted to do to myself I consider to have been a desperate cry for help.

LAW ENFORCEMENT

Any crimes that I may commit as a result of my illness are usually of nuisance to the offended party. Normally it is apparent to others that I am not coherent at the time. I kindly request that I not be cuffed or manhandled if I am arrested. I will be compliant. If the officers that make the apprehension are sympathetic to my plight, friendly conversation and playing music on the car radio is very comforting.

In the event that I am incarcerated I request that I be treated with Navane, as this is the most recent medication that I have used. After 48 hours I expect to be treated as any other prisoner, including the right to refuse further medication or medical treatment. I understand that I am responsible for my actions and must go through the judicial process as any other person. At no point from this time forward do I want anyone to intervene on my behalf except those provided by law.

If it is determined that I am in need of medical treatment I volunteer to go to any Louisiana state run hospital or mental health facility. Only under extreme circumstances will an emergency room be required, as I have no history of drug abuse or attempted suicide by overdose.

Should I be outside the State of Louisiana I appeal to you to contact my nearest relative Colleen Collier at (504) 845-4317

EMERGENCY MEDICAL PERSONNEL

In those instances that I have required emergency treatment, its been because I have failed to use a side effect medication such as artane or cogentin in with narcoleptics. I am particularly susceptible to having adverse side effects to Haldol even with side effect medication.

The above condition can be recognized by my inability to talk and in many cases to walk. My neck muscles tighten up causing my head to tilt upward and my jaw will lock open. My eyes roll up which causes a great deal of discomfort.

If I am delivered to an emergency room or mental health clinic please pass this information on to the attending physician.

ATTENDING PHYSICIAN

If I am in the emergency room, usually one of two conditions exists. I am having an adverse reaction to narcoleptics medication or I am having a psychotic episode. I kindly request that any appropriate medication except Haldol be used to de-escalate my psychotic condition. For the adverse reaction I surmise that arcane or cogent in would be the drug of choice. I want to emphasize that the chance of drug overdose is extremely remote. Please keep this in mind before issuing an order to have my stomach pumped. I went through this ordeal once and don't care to go through it again.

When and if I get to the mental health clinic I kindly request that you respect my philosophy of minimal medication and hospitalization. If alternative care is available such as day crisis units, peer support groups or overnight care facilities these are of my choosing. If hospitalization is deemed necessary I request to be sent to a public facility that accepts Medicare. I am willing to go voluntarily, as this will protect me from being forcibly medicated.

My major concern at the hospital is that Haldol will be used to treat my condition. My experience has been so horrific with the side effects of this medication and that my request to refuse this medication has been ignored that I find it necessary to write this pre-crisis treatment request.

I trust that you will understand that these request are made with the intention of facilitating the treatment that I receive resulting from my illness.

David L. Collier
244 Lovers Lane
Baton Rouge, LA 70806
504-383-9690

December 29th, 1994

Scott Zentner MD
PO Box 1843
Monroe, LA 71202

Dear Scott,

I am writing to you about the forced medication issue from the perspective of the client.

As I understand the current law a person retains his right to a presumption of competency regardless of how he enters the hospital.

This being the case, we at Confident think that a person retains the right to decide whether or not he/she wants to take medication until it is legally determined that he/she is incompetent of making that decision.

In our estimation, the majorities of clients understand the need to trust the doctor with this decision and agree to take the medication. However, many patients think that they have no choice in the matter.

A small percentage of clients prefer not to take the medication. Whether the decision is right or wrong is not the issue. If the client is not a danger to himself, or other, or is not subjecting himself to a gravely disabling condition, we at Confident contend that his/her decision should be respected. Not only should it be respected but protected to prevent a further erosion of control that a person is experiencing at a vulnerable time in their life.

It has been the experience of some of our members that when medication is administered that the nurse will coerce the patient into taking the medication, even to the point of having the attendants force the client to take the medication. It is also not uncommon for the nurse or psychiatric aid to examine the person mouth to see that the medication was swallowed.

Many times there are solid grounds for a person to refuse to take medications as so aptly expressed in Dr. Peter Breggin's book "Toxic Psychiatry".

A person with mental illness deserves to be treated with the same common courtesy and respect that a person at any other hospital would receive. Ultimately a person has the right and responsibility of self determination. We are seeking the support of physician, staff, and administrators in our endeavor to overcome our illness and become restored individuals.

We understand that this takes a great deal of patience and perseverance on the part of professionals. We understand all too well the feeling of wanting to just throw up our hands and saying "To hell with it all." As we become more skilled at dealing with our illnesses we start to realize that our efforts are worthwhile.

A person that has been restored not only helps himself but his friends, family and those around him. We all benefit and carry a lighter burden when our mutual task is accomplished.

We hope that you will understand our position and realize that what we ask is not unreasonable nor unduly burdensome on the staff or doctors. In the future we want to be able to state that "forced medication is a thing from the past."

Sincerely,

David L. Collier
Vice President
Confident, Inc.

Sue Estroff

National Recovery Forum
Columbus, Ohio
April 22-23, 1994

Sue E. Estroff, Ph.D.
Department of Social Medicine
University of North Carolina at Chapel Hill

The papers written by Amy Long, David Granger, Sally Clay, and Garrett Smith are extraordinarily generous and moving. These are narratives from the heart/mind; tales from within. I want to thank each of you for your generosity—for having the grace to tell us so much, and for being such gentle, talented, and wise teachers. I was thoroughly moved by these essays—by moved I mean altered, and shaken awake emotionally. I also mean by moved re-located, changed, re-directed in thought, in my mind. Moved along, shifted in position and in vision.

I was so thoroughly moved by these essays that I literally could not sit still while reading them. The scene is a very early, lush spring day. Everything that can bloom is, and the air is sweet. I was reading your papers in this dawn—pacing around, filled with the power of your words, penetrated by the pain, the humor, the questions that you are and raise, and the warmth and depth of person that you convey so well. Each time I returned to the text, one of you would have written something else that electrified me, and I would have to move around again with the thrill of learning, of taking in you stories, yourselves. Having just reviewed a 300+page academic book manuscript, I was struck repeatedly with the icy, arrogant, wooden vacancy of so much of what we write compared to how you have written. The vividness, the wisdom, the depth of your prose--the stunning clarity and penetrate of what you know and have to say. How numbed, numbing, and pedestrian much of what we have to say is in contrast. We seem, as one disability advocate said of others who are similarly unaware of their impairments, “paralyzed from the neck up.” I had another response to these essays. I felt ashamed, deeply ashamed that any one of you had endured such treatment at our hands. One hopes that this sense of shame will be shared by anyone called a mental health professional upon reading these essays.

What I liked best was your authenticity, the clarity, and the actual craft of your writing. What troubled me most was **how** to respond, indeed if one **can** to revelation such as these. Indeed, we are trying to have a conversation about subjects for which we have no words.

Your thoughts and experiences have generated many questions, along with what I believe to be some lessons and themes. I'd like to spend my time asking those questions and checking out whether I have gotten the messages you sent, gotten the lessons you intended. Along the way, I will make some comments from a

researcher's, hopefully a learner's, perspective about where recovery as related by you leads us.

Like Clay and Granger, I am wary of both the trendiest and of the allure of this 'recovery' business, the search for "*the* recovery paradigm.' I envision a swarm of professionals and researchers milling around these topics and frankly, it worries me. In part, I fear the violence we do to your experience with our constructs and variables, our obsessive need to break everything into parts that can be measured. You have all written about the brute force of madness and of our responses to you, and the exquisite delicacy of reclaiming and reconstructing yourselves. I think we have to be very cautious about dismantling the very process we are trying to understand by the ways we try to understand it. We have for decades produced and relied upon ways of measuring (you and your lives) under the mistaken impression that these were ways of knowing. We have for decades used these ways and missed a great deal of what you have told us about here-you and your stories didn't register, we didn't see it or you, didn't hear it or you. As one of you has said, we always seem to change the subject. I dread the forced translation of the intricacy you have described into variables; I cringe at the unmet able demands for "precision" will be made by the research community and the whole issue will go up in a mist. One of the questions I have for you is how, or if, to proceed with further inquiry into restoration and reclamation processes and experiences.

There will be 'yes, but' responses to talk of recovery/restoration/reclamation—you know the (mostly unspoken) "yes, but" not my son or daughter, "yes, but" you're different, "yes, but" you must have been miss-diagnosed. These "yes, buts" will lead inevitably to attempts to **measure**, i.e., verify and appropriate the experience of recovery from you, when all of us are in rare agreement that we didn't really even know how to or have words to talk about it. And we will appropriate it, and we will run around and say whether a person has it or not, or will or not. At least we will truly. As much as I am ravenous, desperate, passionate to learn more about these processes and experiences, I wonder if we mustn't declare a moratorium on treading on this area until or unless we can do so without doing irreparable damage. Your guidance here would be immensely helpful. Using "recovery" as a clinical or program outcome measure seems to me very premature since we know so little about the multiple factors and forces that contribute. We also have very little access to those persons who have recovered "quietly" as Dale Johnson has said, and gone back to their lives.

Garrett Smith's paper, while perhaps less lyrical than the others, raises some important points, and converges with many of the lessons from Long, Clay, and Granger. Smith writes, "I have" a mental illness, but he says "I am" an alcoholic. He describes the roles and identities in his life—the people he "has been." Why the differences between mental illness and alcoholism, the difference between "have" and "am"? Smith's notion of signals and cues from others and from oneself is very interesting. He makes the point that program rhetoric is no

substitute for these signals and cues, and that in the daily *practice* of a program, there must be repeated proclamations, real evidence that “others believe in their capacity to get a life, to take responsibility, to change.” You can’t fake a signal, and you can’t fool a person who wants and needs so much to believe. Each of you has valued what Long calls “clean communication” with zero tolerance for b.s. Smith asks us to find ways to generate and maintain the *belief signal*. Each of the other authors, in her or his own terms, talks about this, about what we might call *recognition*—being understood, listened to, and about the inner confidence and hope that survives secretly until someone out there *recognizes* you. How do we teach, how do we learn the attitudes, beliefs, and practices that will generate these cues and signals from mental health professionals?

One passage of this paper troubled me greatly. It was Smith’s attempt to ease the fears of mental health staff who feel threatened by empowerment. He says, “Recovery for me does not spell unemployment for you.” The source of my anger knew all too well why he felt the need to write this. We have to ask ourselves, what context, what kind of assumptions about work in this field, what astonishing self-centeredness leads to the need for this kind of placation?! Imagine a cardiologist or a surgeon needing re-assurance from her patients when better, more effective procedures are developed! None of us would tolerate this! Imagine a nurse in a hospital feeling threatened by the increasing use of day surgery and ambulatory care, and even more incredible, imagine a patient who feels compelled to offer consolation or comfort! Why then, do we hear this from Smith? In part because he is a compassionate person, and in part because he is a wise person. He is wise because the real culprit here in my view, is a mentality, a tradition, a culture of power imbalance and forced dependence. What we see here I think is a lingering example of what patients have always done, have learned to do. To recognize that the needs of the system supersede their own; that if they want to “grow up” in Smith’s analogy to parenting, that the parents’ fears of loss of control or power need to be assuaged or there will be hell to pay. As Granger says wryly, “Don’t let your treatment interfere with your recovery.” What kind of a system of care is this?!

While offered in distinctive prose and from different perspectives, there are some consistent themes, some profound lessons in these narratives.

- **Recovering is a process:** The terms used include: Journey, return, Re-association, re-connection, search, “herky jerky course” (Smith) re-joining “a wounded soul wandered away” coming back, (Long) linear/non-linear, “returning to consensual reality” (Granger)
--this is a lifelong process, “a way of thinking about life” There may be no identifiable beginning and hopefully there is no end also how critical I is, when to embrace, when to let go, “respectful leaving” (Long), how long it takes

- Having a major mental illness is a **Transformation, it is life changing and identity altering:** (Granger): “What now? What will I be?” (Clay), “From the experience of madness I received a wound that changed my life.” “If we are recovered, what is it we have recovered from? If we are well now and were sick before, what is it we have recovered to?”
- **Faith in one’s inner experience, self trust, and self belief is a key component of recovering:** “I had faith in my mind and trusted it.” (Clay), “Tell me something I can believe’ (Granger), belief that it is possible to re-connect, Hope. “A felt belief that things can get better.” (Smith) (Long) “I dared to recover in spite of my diagnosis, for I held the faith inside that was much more”
Each had an often **secret, internal core of belief in themselves and in their worth, reality, and possibility for a life of meaning.** We need to know much more about how to locate and nurture this sometimes well hidden self trust
- Recovering involves coming to terms with the **reality** issue, the **depths of the altered state, the nature of madness as primary experience:**
Long, Granger, and Clay discuss in part where they went, their different realities.
Long was concerned about lonely flowers and confused shoes; (Clay) “madness as its own reality, compelling, secrets; a hell of darkness and despair”;
“Although we have been broken, we have tasted the marrow of reality.”
Clay gives “credit to madness itself”
(Granger) the loss of “consensual reality”; I have a chemical imbalance I really didn’t experience those things,”
- The **emotional**, not just cognitive nature of the experience: Long “the broken heart of schizophrenia” Clay describes the “shame,” she felt ‘defeated, degraded, debilitated, desperate, sick, evil” because of the meaning others ascribed to her experiences, when these intimately meaningful experiences were dismissed as symptoms, as cognitive abnormalities, she describes also the need for a “psychology of the heart;” Granger’s powerful surmise, “Here is an insight! The entire human drama of love, suffering ecstasy and joy, just chemistry.”
- **Spiritual nature of the experience and the spiritual fuel for recovery:**
Long “the third eye” and “forgiveness” (of herself and others); Granger, “making peace“; Clay describes the beginning and continuation of her own restoration with her study and practice of Buddhism, of the integrating and calming force of her “spiritual outlook that enabled” her to go on.
- **Vulnerability and delicacy, yet force and durability of the process,** how acutely aware each of them was about their need for at least one

other, a benevolent, affirming other, and how much damage could and was done by malevolent, indifferent others; the vital “life and death” struggle that requires some collaboration from others.

Long, the importance of asking and listening, the importance of a guardian of her hope, the therapist who held the hope and faith “until I could take it back again” Perhaps we need to re-think the value of psychotherapy, of skilled psychotherapists in the process of recovery.

- **Language and diagnostic categories are dangerous and debilitating;** the costly convenience of labels. How do you resist successfully these labels?
- **Race** and other forms of **oppression** and **exclusion**
Granger had to go to the state hospital to escape racism; Long sought “feeling like nine out of ten instead of one in ten” How do we do this without herding, lumping, grouping you into patienthood? Material resources are also a necessary though not sufficient component of the process, it isn’t all spiritual, and it is practical as well
- **Owning the process, issues of responsibility:** Granger “Recovery is ultimately my work, my responsibility. Smith “I’ll take all the help I can get, but I want to be my own case manager.” Clay “the form my emotions take and the meaning I give them are my responsibility.’
- The central significance of **regaining a sense of meaning and purpose.** Clay, a life of practicing wisdom and compassion; Granger, “What I want and need, is access to a life worth living.” Smith talks about the simple necessity of “getting a life”
- **Messages for mental health service systems**
 - The need for Creative, daring leaders
 - Increased attention to staff training, especially about therapeutic relationships, healing relationships
 - Better clinical supervision is essential
 - Mental health staff as advocates and watch dogs over others
 - We should be more explicit about the multiple, sometimes conflicting roles played by the system, e.g., social control versus helping to heal

And finally, a word or two about what was not said or written. There was very little anger in these essays. Perhaps that was deliberate, or perhaps you have learned that if we are to hear you, anger has to be controlled or communicated in another way. Involuntary treatment does not seem to have been a central focus here. It was mentioned, but was not a focal point of anger, injury, or outrage. The accounts were largely un-gendered. Gender did not enter into these narratives in such a way that one could learn about how being male and female

influences the experiences of madness or of recovering. Likewise, the sensate, bodily dimension of illness and of healing was muted. Class and race were part of one narrative, and left me wondering about their influence for the other authors.

The narrative structure of the essays themselves revealed a distinct difference in relation to our counterpart—the medical or clinical history in the chart. The latter start always with categories of person: age, race, sex, diagnosis. These are our locators and definers. The authors here often did not tell us their demographics—they were not all that relevant. What they told us transcended in some ways, and certainly overshadowed those categories.