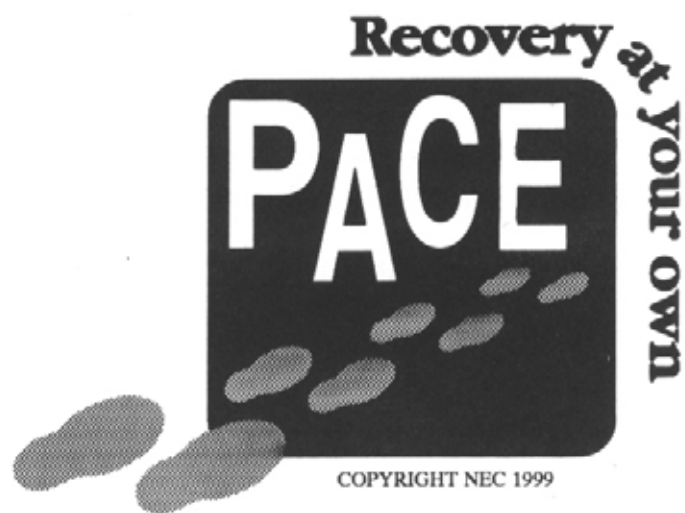




Personal Assistance in Community Existence

◆ A Recovery Guide ◆



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About the Authors



Laurie Ahern and Daniel B. Fisher are the Co-Directors of the National Empowerment Center, Inc., (NEC) a national technical assistance center which provides information on empowerment and recovery from mental illness.

Daniel Fisher is a person who has recovered from schizophrenia. He was hospitalized several times prior to becoming a psychiatrist and is one of the few psychiatrists in the country who openly discusses his recovery from mental illness. He received his AB. from Princeton University, his Ph.D. in biochemistry from the University of Wisconsin, and his M.D. from George Washington University. He was a neurochemical researcher at the National Institute of Mental Health and is a board certified psychiatrist who completed his residency at Harvard Medical School. In addition to his position as Co-Director at the National Empowerment Center, Inc., he is a staff psychiatrist at Eastern Middlesex Outpatient Center, Riverside in Wakefield, MA.

Laurie Ahern was hospitalized and labeled with mental illness at the age of 19. She recovered and went on to become the managing editor of four newspapers and a free-lance writer for the Associated Press, The Boston Globe, and several other national publications. She has won national awards for her investigative and editorial writing. In addition to being Co-Director of the National Empowerment Center, Inc., Laurie is the vice-president of the *National Association of Rights Protection and Advocacy* (NARPA).

Both Dan and Laurie conduct workshops, give keynote addresses, teach classes, and organize conferences throughout the country for consumers/survivors/ex-patients, families, and mental health providers to promote recovery of people labeled with mental illness. They recently were named co-recipients of the National Mental Health Association Clifford Beers Award for 2002.

PACE

How Personal Assistance in Community Existence facilitates people's recovery from "mental illness"

People can and do recover from severe emotional distress known as "mental illness." However, most mental health services - both inside the hospital and out in the community - operate from a belief that mental illness is a lifelong, permanent condition from which people never fully recover. The underlying goals of what are known as the medical and/or rehabilitation models are stabilization, maintenance, and an increased level of functioning while remaining mentally ill.

Recovery research tells us that, given the right combination of attitudes and supports, people can fully recover from mental illness. As a result of this research and based on the National Empowerment Center's Empowerment Model of Recovery, we have developed a new way of assisting people in their recovery called:

Personal Assistance in Community Existence, or PACE

*Client is but one of several terms such as consumer, recipient, or person labeled with mental illness, which describes a person who is using mental health services.

PACE is based on the underlying principle that people recover from what is known as mental illness through voluntary forms of assistance directed by the individuals themselves. The cornerstone of this assistance is the development of trusting relationships, which in turn allows people to (re)capture their dreams and enables them to (re)gain a valued social role.

Consciousness raising is paramount in the implementation of a **PACE** program. One cannot superimpose new services over an old philosophy/belief system and expect different outcomes. The **PACE** model embodies the values/attitudes of self-determination, an absence of coercion, and the over-arching belief that severe emotional distress is a temporary disruption in a person's life from which a person can recover.

This handbook is designed for all of those affected by mental illness. It is for administrators and providers who want to put into practice the latest information on recovery. It is for people who have recovered or who are recovering and want to assist themselves or others. It is an invaluable tool for teachers, trainers, and family members.

In an easy to follow format, we review the principles of recovery which have emerged from the latest research. We illustrate how the Empowerment Model of Recovery provides both those giving and those receiving assistance with an optimistic vision of their future, and give ways to apply **PACE** principles in any setting where people are recovering.

Principles of PACE

The results of research into recovery

People do fully recover from even the most severe forms of "mental illness"



"Mental illness" is a label for severe emotional distress, which interrupts a person's role in society, helps in a person's recovery



People can and do yearn to connect emotionally with others, especially when they are experiencing severe emotional distress



Trust is the cornerstone of recovery



People who believe in you help you recover



People have to be able to follow their own dreams to recover



Mistrust leads to increased control and coercion which interfere with recovery



Self-determination is essential to recovery



People recovering and those around them must believe they will recover



Human dignity and respect are vital to recovery



Everything we have learned about the importance of human connections applies equally to people labeled with "mental illness"



Feeling emotionally safe in relationships is vital to expressing feelings, which aids in recovery



Understanding the meaning within severe emotional distress helps with recovery

The National Empowerment Center's research into how people recover from "mental illness"

Over the past several years the NEC has been conducting research into the factors most important to people's recovery from mental illness (Fisher and Deegan, 1998).

Retrospective studies involving structured interviews of people who have fully recovered from mental illness have revealed themes that fall into five major categories.

1. **Recovery Beliefs:** Most of all, we find that for people to recover, they and the people around them must believe that they are capable of recovery. They need to believe, as do others in their lives, that they are capable of once again running their own life, of having dreams, friends, a job, and a place of their own. *Never give up.*

Believe that people will recover: An essential aspect is that people believe they will reach a point when they are no longer mentally ill; this is in contrast to the belief that people are forever recovering.

Hope is crucial to recovery: "None of us would strive if we felt it was a futile effort."

Believe in yourself: "One of the elements that makes recovery possible is regaining a belief in oneself."

Turning toward their future: People also are motivated to feel they are developing elements of themselves they had not possessed prior to their being labeled, not simply returning to their condition prior to being labeled.

2. **Recovery Relationships:** People say that entering into close, trusting relationships was vital to their recovery. People who have recovered tell us that they found someone who believed in them. They say it is important to be with people who respect and understand them. These types of relationships helped people recover because they felt whole, human, alive, and in control of their lives.

Someone who believed in me: One interviewee stated of his therapist, “he would validate that I had a lot to offer and was positive that I was a unique individual...” Another said: “she believed I could make it.” Another described that he could detect belief signals from people that really understood him. These were people who “believed in [my] capacity to get a life, to take responsibility, to change.”

Someone who never gave up: This level of persistence and long-term commitment to another person’s welfare is often cited. One person described her doctor: “she followed me through the whole thing...she still believed in me... she never gave up.” Another said it helped when she urged her counselor, “don’t give up on me, I am a person too.”

People who make you feel safe are people you can trust: This theme is essential to many who felt they could express themselves more freely in such a relationship. “He knew what to say to make me feel safe and I trusted him.” Safety can also involve having someone to help solve problems: “Let’s just try to figure out what’s going to happen.”

People who have been through a similar experience: People feel more comfortable and accepted by someone who has been through a similar experience. This is analogous to people who have recovered from addiction being the best counselors for people who are just

starting to get sober. This is why consumer-run services are so appealing and why consumers working as providers fill a special role.

People who are able to be human: One person described her therapist as human, fallible, open to correction, and not god-like. Another requested that above all else his therapist be real, to which the therapist said he would try. Humor was cited as an important factor. As one caregiver was described, “he would keep me laughing when I saw him...he made me laugh.” Most interviewees found professional distance a barrier.

People who allow you to recover at your own pace: In clinical settings this means there needs to be collaboration between the people recovering and the people assisting them. This allows the formation of a recovery plan, which is based on the dreams, and goals of people recovering rather than the goals of the staff. This approach improves motivation because people work much harder to realize their own dreams and goals. This must be done in a non-threatening, non-coercive setting.

People who care about you: “For the first time in many years I felt that someone cared about me. In my life there is nothing more important than my friendships.”

3. Recovery Skills: Once people and their network have come to believe in their capacity to recover and believe in themselves; they can acquire many of the skills needed to manage their own lives and their emotional distress. A primary skill is learning how to connect on an emotional level. Learning how to express anger, sadness, joy, love, and fear helps people make friends and gain control over their lives. Self-managed care is the set of skills for managing severe emotional states without the use of medication. At times, one may need to be on medication and learn how to use it in an informed, voluntary way as one tool among many toward recovery.

Connecting with people at an emotional level: Many people stated that forming emotionally meaningful relationships was vital to their recovery.

Self-care techniques: These are the things one can do for oneself. People found it helpful to discover what made them feel good, such as writing, painting or taking walks. Holistic health offers many self-care techniques such as meditation, exercise, yoga, and nutrition, to name a few.

Taking responsibility for yourself: To progress, it is important to take responsibility for some part of your difficulty and your recovery. Unfortunately, the medical model absolves people of all responsibility for their problems and their solutions. Perhaps the most extreme example of this position was a consumer who told his parents he could not do the dishes because he had a chemical brain imbalance. As one person in the study said, "you have to realize what responsibility you have for your problems."

Forgiving yourself: A potential risk involved in taking responsibility is to overly blame yourself for your problems. This can lead to self-punishment. Understanding that there are events in life, which are beyond people's control, helps in self-forgiveness. One participant stated, "I learned to go a little easy on myself...to be self-forgiving." It is also easier to forgive yourself when you have friends who are able to forgive you.

Setting personal goals and achieving them: Part of taking more responsibility for one's own recovery is through setting and fulfilling one's own personal goals. Some people in the NEC study set a goal of working out to get in better shape and gain more control of their bodies. Others said it was important to prioritize their tasks so they could do the most important things first. This gave them more control of their time.

Expressing uncomfortable feelings: People in our society have been told they should have stiff upper lips and not show their feelings, especially those of sadness, anger, or fear. Being able to express these feelings is vital to recovery.

4. Recovery Identity: We need to leave behind the fragmented, isolated identity of a mental patient and regain the feeling of being a full human being. This positive identity is important to the recovery of a valued place in society. This process occurs through being valued in relationships, through having successes, and through valuing oneself.

A person, not a mental patient: One person emphasized, "I was a person before I was a patient."

Recalling past successes: "I would say I have done this before...[that's] a self-building mechanism."

Overcoming stigma: People find it helpful to be part of the consumer/survivor/expatient movement* which emphasizes pride. Being part of a movement allows people to counter the negative stereotypes and attitudes directed towards people labeled with mental illness. By urging the use of people first language rather than terms such as "The mentally ill", people labeled with mental illness can see themselves as whole human beings.

Feeling whole: Many said feeling like a whole person again was important in their recovery.

5. Recovery Community: It is vital that people who are recovering or have recovered be part of a community, which provides each person with valued social roles that reinforce the factors shown above. The c/s/x

*The consumer/survivor /expatient (c/s/x) movement is an international network of people who have been labeled with mental illness and who are working together for advocacy, social and political support, and recovery.

movement, with its collective voice, has given a positive identity, a connection, valued roles, and empowerment to many of its members. Helping others to recover dignity and rights can help people with their recovery.

Work is frequently a good means of having a valued social role. “I sincerely believe that work is therapy. It gives you a reason to get up and get moving.” “Work makes me feel I am contributing.”

Helping others gives meaning to people's lives: One person said, “helping people gives my life meaning and purpose.” This is the appeal for consumers to return to work in the mental health system as providers. One person in the study stated that after returning to school to become a mental health worker, “For the first time in my life feel empowered... When I wake up in the morning, I feel full of excitement and wonderment...I want to go into my job and scream, if I can do it, you can do it too!”

Additional research over the last 30 years has pointed to social, cultural and economic factors as playing a large role in the incidence and recovery from mental illness. When the mental health system and the society believe that people can recover from even the most severe forms of mental illness, the outcomes are more positive.

Dr. Nancy Waxler conducted research which showed the rates of recovery from schizophrenia were much higher in the developing country of Sri Lanka than in England. She concluded that where schizophrenia is viewed as an acute disorder from which people are expected to recover, as from any other acute disorder, people did indeed recover (*Waxler, 1979*).

In the 1940's, several visionary mental health administrators in Vermont devised a new rehabilitation program for long-term patients at the Vermont State Hospital. The hospital staff were given the training and structure to create a democratic ward, emphasizing trust, compassion, and hope. In addition, an ex-patient group in the community, called Helping Hands, was started which played a valuable role in patients' adjustment to community life. They provided encouragement and role modeling to the patients and staff in the hospital. They educated the community at large to help reduce stigma and to facilitate the patients' transition into the community. They gave peer support in the community to people who were discharged. This novel approach became known as the Vermont Story. (Chittick et al, 1961). Thirty years later, Dr. Courtney Harding and associates compared the outcomes of the consumers from the Vermont Story with a group of consumers from Maine with equally severe histories. The researchers concluded that the recovery rate was much higher in Vermont because there was an emphasis on self-sufficiency, self-determination, and community integration. On the other hand, Maine had maintenance, stabilization, and medication compliance as their goals (*DeSisto, et al., 1995*).

The World Health Organization's cross-cultural, multi-country study of schizophrenia concluded that there were significantly higher rates of recovery in developing countries than in industrialized countries (*WHO, 1979*).

Dr. Harry Stack Sullivan was one of the earliest clinicians to question the down hill course predicted for people labeled with schizophrenia. From his work with patients and his research he concluded that people could recover. In addition he attributed much of their recovery to their belief that they could recover as well as to their ability to rejoin society. "If the patient has the fore conscious belief that he can circumvent or rise above environmental handicaps, and if this belief is the presenting feature of a comprehensive mental integration, his recovery proceeds. If no such reconstruction is accomplished, the patient does not recover" (*Sullivan, 1962*).

Dr. Loren Mosher, with a grant from the National Institute of Mental Health, opened Soteria House in California in 1971 as a non-medical alternative to hospitalization for the treatment of psychosis. Residents were experiencing their first psychotic breakdown from shared reality of their usual social setting and were diagnosed with schizophrenia. The mission of Soteria House was to "provide a simple, home-like, safe, warm, supportive, unhurried, tolerant and non-intrusive social environment;" mostly by "being with" the residents. The house staff believed sincere human involvement and understanding were critical healing interactions.

The results were startling; Without the use of medication, Soteria House residents were able to recover from psychosis within six weeks. After a two year period, a higher percentage of the Soteria House residents were living independently and had significantly fewer hospital readmissions compared to those treated with medication and hospitalization (*Mosher, 1999*).

"It is generally believed that a treatment that is more effective than its alternative will be used, but psychological treatments for schizophrenia and other psychotic reactions have been avoided despite the evidence for their effectiveness from the time of 'moral treatment' to the present. Less effective, even destructive treatments have been seized upon, in part because they do not require understanding these patients. Understanding schizophrenic persons means facing facts about ourselves, our families, and our society that we do not want to know or to know again (in the case of repressed feelings or experience)" *(Karon, 1992)*.

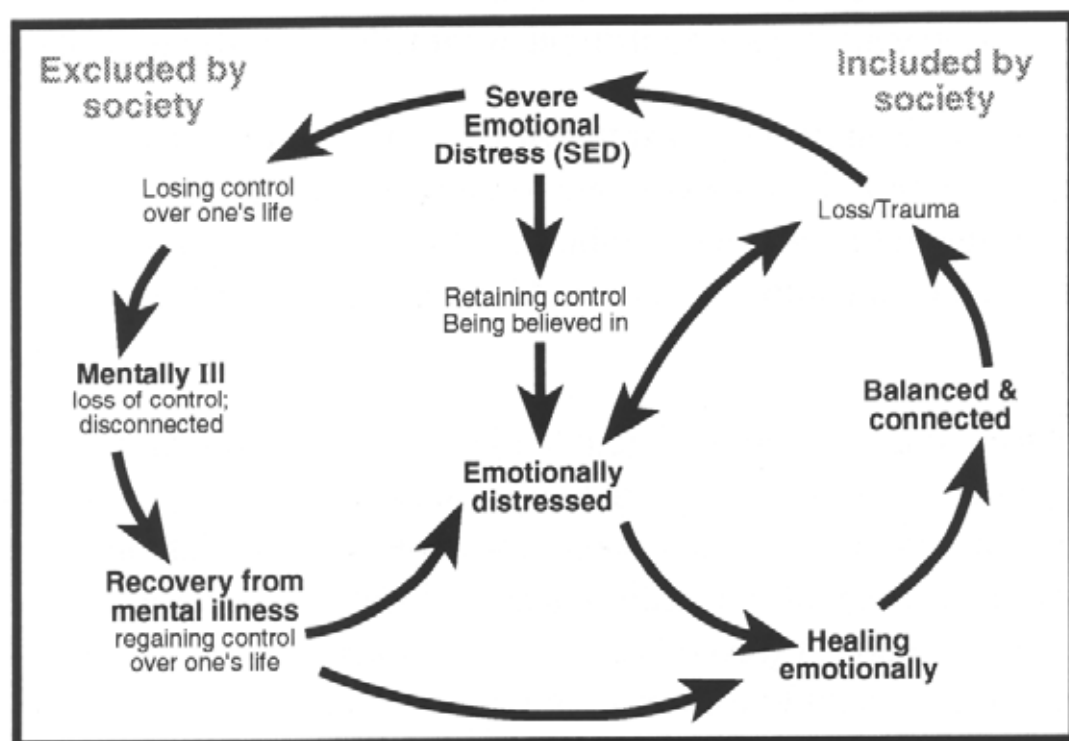
In the city of Falun in Sweden, from 1992 to 1996 psychiatrist Lars Martensson practiced what he called "reverse psychiatry." First time psychotic patients worked with a psychiatric team that viewed psychosis as a human crisis which could be overcome, did not believe in the use of neuroleptics, and avoided hospitalization. As a result, none of the patients received a diagnosis of schizophrenia and all were able to overcome their psychosis and return to the community.

"In normal psychiatry, a psychotic patient is hospitalized, separated from the family and finally, after some time, is released with maintenance neuroleptic drugs. The family is 'educated' to help make sure the patient takes the drugs she 'needs'...With reverse psychiatry, on the other hand, it appears that most persons who would become schizophrenic with normal psychiatry, are able to overcome psychosis. In other words, with the right help at an early stage, the development from psychosis to schizophrenia may be prevented" *(Martensson, 1997)*.

Author, researcher, and ex-patient Judi Chamberlin and associates have carried out essential research to define the term empowerment. Their research showed that when a person is empowered they are able to take control of the important decisions affecting them. They are assertive, and view themselves as competent members of society. She concluded, "If anything defines the public (and professional) perception of 'mental patients', it is incompetency. People with psychiatric diagnoses are widely assumed to be unable to know their own needs or to act on them. As one becomes better able to take control of one's life, demonstrating one's essential similarity to so called "normal" people, this perception should begin to change. The client who recognizes that he or she is earning the respect of others increases in self-confidence, thus further changing outsiders' perceptions. There are genuine benefits when clients begin to take control of their own lives, and when practitioners become guides and coaches in this process, rather than assuming the long-term, paternalistic role of supervisors"

(Chamberlin, 1997).

PACE is based on the Empowerment Model of Recovery



Empowerment Model of Recovery from Mental Illness

by Daniel B. Fisher, M.D., Ph.D. and Laurie Ahern
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The above diagram describes our model of recovery based on research we and others have carried out. This model describes the process of how people are labeled mentally ill and recover.

Balanced & Connected: People start out life balanced and whole in utero. Balanced and whole is a frame of mind and state of being. It is thought that we are constantly striving to return to such a state of well being through our connections with those around us >

Loss/Trauma: Inevitably we all experience loss and trauma during childhood. Some of these experiences are more traumatic than others such as loss of a parent, physical and sexual abuse, poverty, and racism. These traumas are remembered deep inside and often result in >

Emotionally Distressed: This degree of distress can take the form of grief, fear, sadness, but often does not completely interrupt the person's fulfilling their usual social role such as student, lover, worker, and/or parent. People are still seen as full members of society and retain control over the major decisions in their life. To gain relief from this distress, they engage in >

Healing Emotionally: Since suffering is universal, healing also is universal. People heal in a variety of ways, some individually, some in groups. Healing generally involves finding meaning and regaining a more balanced and whole feeling. However, for some people, loss and trauma result in a state of >

Severe Emotional Distress: There may be more dramatic problems in feeling and thinking such as paranoia, feeling that the TV is talking to them, or suicidal feelings. However, these distortions in thinking and feeling do not result in a label of mental illness if the person has sufficient socio-cultural supports, resources (such as housing), and coping skills to maintain their place in society and retain control of their life. If, however, in some situations there are not sufficient supports, resources, or skills and the person is unable to maintain control, they may need more intense assistance. Typically that has meant the person is labeled >

Mentally Ill: Then they are most often placed in a psychiatric hospital and a course of intense professional treatment begins. The person loses their major role(s) in society and begins the "career" of a mental patient. It is much more difficult to recover once a person is labeled mentally ill because there is recovery from the trauma of being excluded from society, from being on disability, as well as from the severe distress which started them on that course >

Recovery from Mental Illness: Recovery is attained through the combination of believing one will recover, becoming involved in relationships with people who believe they will recover, learning recovery skills, and entering into a valued role in society. Their identity shifts from "mental patient" to whole person. ■

What people are told when they are told they are mentally ill

Unfortunately a majority of people who are labeled mentally ill have heard a set of phrases that are pessimistic and interfere with recovery. These phrases need to be countered in order for recovery to proceed.

Medical/Rehabilitation Model

"you are mentally ill"

"your mental illness is caused by a genetically or chemically based brain disorder."

"your disorder is permanent"

"you should not work until you are symptom free"

"you must take your medication for the rest of your life"

"you must remain under the care of professionals forever"

"if you avoid stress you might be able to cope"

Empowerment Model

"you are experiencing severe emotional distress which interferes with your life in the community"

"your distress is due to a combination of losses, traumas, and lack of supports"

"you can completely recover"

"begin meaningful work as soon as you can as work helps with recovery"

"you may find medication helpful while you are learning self-management skills and alternative ways of recovering from severe emotional distress"

"you will be able to gain your main support from peers and friends rather than professionals"

"you can once again have dreams, meet challenges, and have a full life"

Medical/Rehabilitation Model

"you are your illness"

"as a result of your illness you are unable to express feelings or form relationships"

"you do not have the rights or responsibilities of others"

"you are more dangerous than others in society"

"you cannot have a significant other or have children"

Empowerment Model

"you are still fully human"

"you are experiencing such extreme feelings that you feel it is unsafe to show them. Eventually you will feel safe enough to understand your feelings and those of others and form close relationships"

"you are entitled to full civil rights"

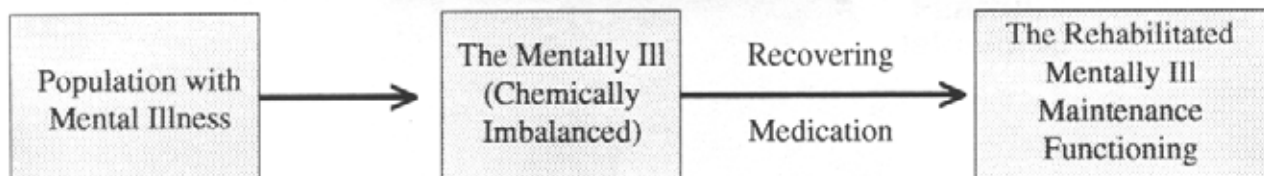
"you are not more dangerous than the rest of the community"

"you can have a significant other and have children once you have progressed in your recovery"

How the Medical/Rehabilitation model still segregates people labeled with mental illness

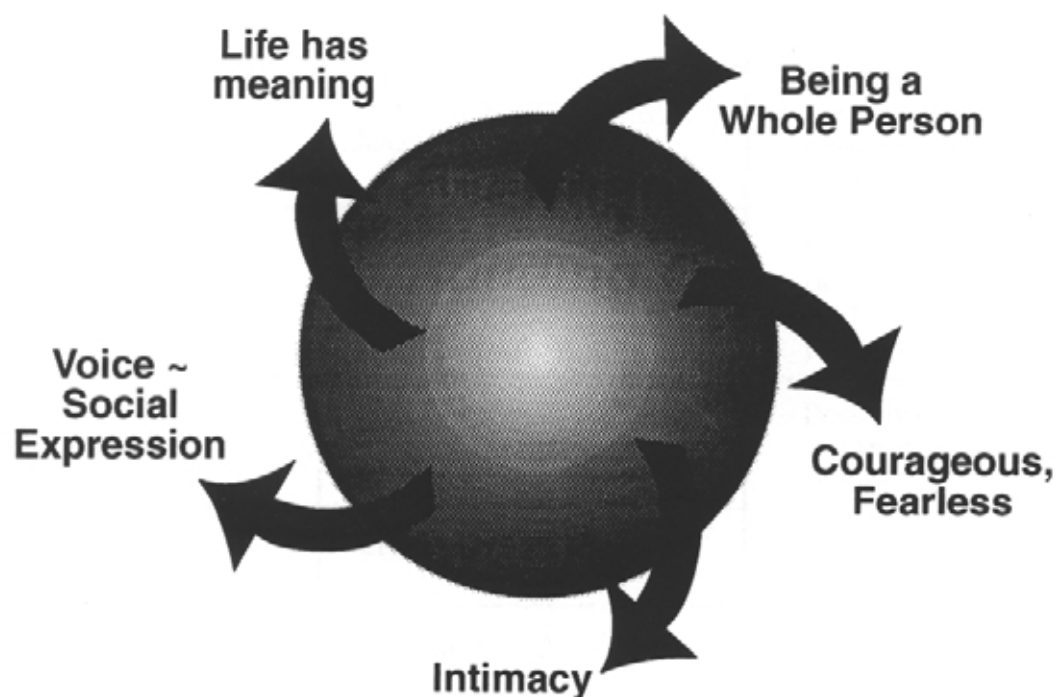
The medical/rehabilitation view of recovery from mental illness is that people regain some social functioning, despite having symptoms, limitations, and being on medications. Although they can become "high functioning" they remain forever mentally ill. They are forever separated from the rest of society because they believe they are chemically and genetically flawed, and imbalanced - a state from which they can never fully recover.

Medical /Rehabilitation Model of Maintenance of the Mentally Ill



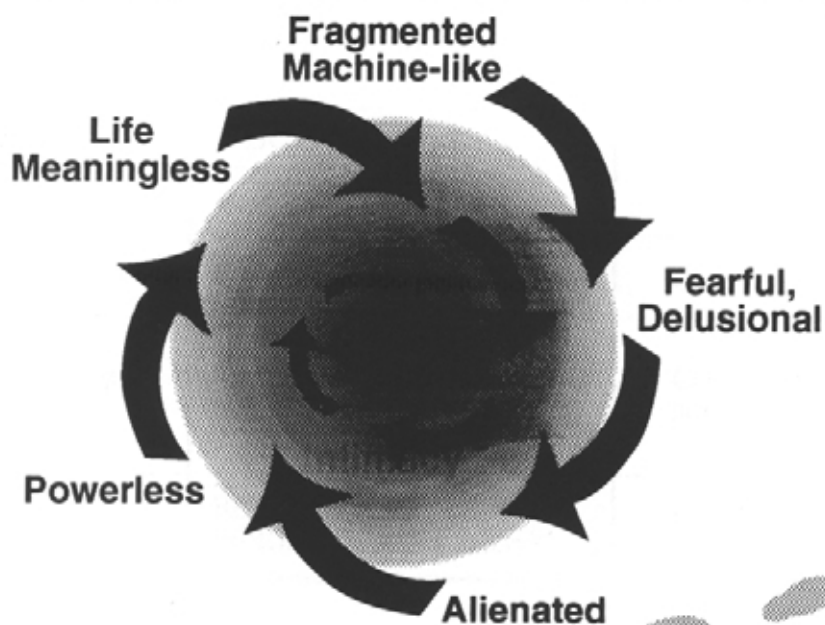
PACE/Empowerment Approach

Self-Building Cycle



Traditional Mental Health System

Self-Destroying Cycle



Comparison of Traditional Mental Health System (TMHS) vs. PACE

Values/Assistance	TMHS	PACE
Could anyone become mentally ill?	No: Labeled people are not equally human	Yes: Therefore we are all equally human
Cause of mental illness	Permanent brain disorder	Severe emotional distress and loss of social role
Recovery	Lifelong process	Complete recovery possible
Goal of help	Maintenance	Full recovery
Control	Coercion by team; external control	Person centered, voluntary; control by self
Pace	Set by team	Set by individuals themselves
Relationships	Professional distance	Peer connections
Primary assistance	Medication	Person who believes in you
Main social setting	Professionally-run	Peer-run
Rights	Violated often	Respected
Outcome	Dependency; lacking responsibility	Self-management; gain sense of responsibility
Choice of help	Little choice and narrowly medical	Full choice; consumer-run, psychosocial, therapy
Primary person	Case manager	Personal assistant
Housing and money	Compliance with services required	Compliance with services not required
Function of medication	Required for lifelong maintenance	Used as a tool, by choice

**The following are examples
of the PACE approach to
helping and assisting
people who are in
frightened, angry, or
upset emotional states**

*No matter how upset or
away from reality
someone seems to be,
remember, there is
always a person inside.*

A Caring Person Helped Me Feel Safe

I was 25, and in a state of great fear. I was dropped off at the Bethesda Naval Hospital emergency room by housemates I barely knew. They sped off, leaving me without any friends, family, or identification. I was too scared to talk.

One by one, various clinicians approached me, starting with the doctor in charge, and gradually working down the ladder. Each fired a series of questions at me. Each seemed little concerned with who I really was inside; they were intent on filling in their forms. Seeing no reason to answer their questions, I remained silent. They sat me in a wheelchair and wheeled me into a corner while they decided what to do next. Meanwhile, a young corpsman, the lowest-ranking clinician in the emergency room, stopped over to see me. He looked at me for a long time without speaking. He looked at me in a caring, focused manner. It was clear in his eyes that he cared about the me deep inside. In a very gentle voice he said, "Hi, my name is Rick. I can see that you are in a lot of pain. Could you nod your head if you hear me?"

I nodded, and at that moment felt that I could return to living with other people.

~ Daniel Fisher

Karon's Bowing Man

Dr. Bertram Karon was providing therapy to a man diagnosed with schizophrenia. One of the man's symptoms was frequent bowing. When he was asked why he bowed he said he did not bow. The therapist demonstrated a bow and said, "but you do this and this is bowing."

The man repeated, "No, I don't bow."

Therapist: "What is it?"

The man: "It's balancing."

Therapist: "What are you balancing?"

"Emotions."

"What emotions?"

"Fear and loneliness."

When he was lonely he wanted to get close so he leaned forward. But when leaning brought him close to people, he got scared and pulled away by straightening up. There is always personal meaning in behavior which seems the most unusual. The man completely recovered from schizophrenia in eight weeks (Karon, 1992).

Dr. Sandor Bockoven

Dr. Sandor Bockoven had received his training in the premedication days. If a patient in the hospital was furious he used his communication skills, instead of medication, to calm them down. He would arrange his office so he and the patient were the same distance from the door. He used soothing tones, and always kept his eyes at or below the level of the patient. His success was high (Bockhoven, 1963).



A Tale of Two Boys



This is a tale of two boys – two young men to be completely truthful. One is well known to me - the son of a close friend of mine - we'll call him Jack. And the other, well, he is not so well known to me - only through a few anonymous phone calls to the National Empowerment Center. We'll call him Karl. (The names have been changed for this tale to protect the innocent, and I'm sorry to say the not-so-innocent anymore). And for anyone who might wonder, this is a very true tale.

Once upon a time, there were two wonderful, happy, smart young men. Both were in college, living on their own - testing the waters - testing themselves. New friends, new freedoms, new loves, new ideas, new temptations - new everything. Both had the world at their feet and were limited only by their own imaginations of what their lives might be about, might become. Then crash.

Well, as I said, Jack is a child I have known for his entire lifetime. I watched him grow inside his mother, I watched him take his first steps and say his first words. I watched and I'm still watching.

Karl I met just months ago - via the NEC 800-line. Karl I don't know - yet I do. The parallels between these two young men are eerie - yet the outcomes so different - so frighteningly different.

Crash, crash, crash. It seems to happen at that age, doesn't it? Eighteen to mid-twenties. And it happened to Jack and Karl.

Jack was at a college in New England and Karl was in school out on the West Coast. I remember when Jack was fifteen years old, he and a friend were car-jacked at knife-point. Even though they caught the man - and he was sentenced to seven years in prison - Jack never seemed to quite get over it. He would not stay alone in his house at night, always locked his car doors no matter where he was going, and would not travel without a cell phone.

When Karl called me at the NEC, he told me about a time when he was an exchange student in high school, how he had been held up - mugged - alone in a foreign country - and had never been so terrified in his life.

I tell you these things for a reason.

Jack has always wanted to be a journalist, and Karl told me that music has been his passion as long as he could remember.

Both had such high hopes, such big dreams. Only one dreamer remains. The other dreamer died with his dreams when he was labeled "mentally ill."

Each experimented with drugs for the first time in college - Jack went to a concert and tried LSD. Karl started smoking marijuana with the band he formed in college. Pandora's box was now open. Paranoia and fear trickled in, replacing logic. Men were after them, people were talking about them. They could not sleep, they could not eat. Fear was the dominating factor in their lives. The drugs were gone, the high was over, the trip had ceased - but the demons remained.

Jack called home and Karl's friends called his parents. This is where the road divides. This is where the similarities end. This is where one has a breakdown and the other has a breakthrough.

Jack's mother knew he was frightened. She told him to leave college and come home. She felt she needed to help him feel safe again - the only way to bring him out of this deep paranoia.

Karl's parents told him to come home. They too knew he was frightened and needed help. They brought him to the best psychiatrist. He was hospitalized. He was medicated. He was told he had a chemical imbalance of the brain. He was labeled. He was told that college was too stressful for him, he could never return. He tried to commit suicide. He lived, but his dreams, his dreams died.

Jack's mother and friends stayed home with him, listened to the fears. He went off caffeine, ate healthy foods and took long, warm baths. He had acupuncture, massages, and found a therapist who did not label him. They took walks together, they talked. Slowly, very slowly, he felt safe enough to come back. And then they worked on why he left, why this reality was so frightening that he needed to leave it in the first place.

Jack - well, Jack is back living at college. He started working out and volunteers in a home for mentally retarded adults. He told me several things since his breakthrough: "This is the most painful thing I have ever experienced in my life and I would not wish it on anyone - but I would not change a thing. Better I deal with these issues now then wait until I'm forty or fifty. I feel stronger than I ever have. I've learned so much about myself, I still have fears but I control them - they no longer control me."

Karl called me after he walked home from his last day at the day treatment program. "I saw a sign on a restaurant window - they were looking for a dishwasher. Do you think I could handle that?"

I cried. ☐

~ *Laurie Ahern*

The PACE Values I Live By

by Daniel Fisher, M.D., Ph.D.

I am a uniquely human being: I and other humans around me exist on a spiritual, mental, and physical levels at the same time. Each of us has our own thoughts, feelings, and awareness which we can partly share with each other and partly keep to ourselves. I am more than a chemical machine. I am a person who has recovered from experiences labeled as "mental illness" and from the treatment I received. I am as worthwhile as any other person.

I can say yes to life: There is a brighter day ahead. No matter how dark the present, I can dream, hope, and see myself having a future, because being human means I am not condemned to relive my past. I can learn to trust myself and to forgive myself.

I can make decisions about my life: In fact, only I can make the most important decisions about my life. Others can supply tools and supports but I must manage my own life. I feel motivated to carry out the decisions I make because they are connected to who I am. I am unmotivated to carry out someone else's plan of who I am.

I will direct my own recovery: There is an old expression "Doctors dress the wound while God heals them." For me that means that doctors and other helpers can reduce symptoms but each person directs their own recovery. Treatments, advice, and support are useful when used by you as part of recovery. Just as severe emotional distress affects all levels of me, recovery takes place by my attending to all levels.

I can have meaningful relationships and work: I have a right and a need to be with people who care about me and value me for myself, people who want me to be myself. Similarly, I can care about and respect them. In work, I need to feel I make a positive difference in the lives of the people around me; I need to feel that my efforts fulfill goals I have for myself.

I can make a difference in my community: I have important things to say. I can affect other people around me. I expect people to listen and think about my words. I am a person and expect respect. I can then respect others.

I am connected to all living beings: The earth and the sky touch us all and connect us all. I need to fight the urge to crawl into my shell. What goes around comes around. Everything I do affects others and vice versa. "We are all one family under one sky."

I can express my feelings and thoughts: I have the capacity, right, and need to express my innermost feelings and thoughts and be respectful of others' rights and needs. My fears and joys have meaning to me and those I love.

I can love and be loved: I am capable of giving and receiving love. I can respect and value others and they can respect and value me. I agree with the lyrics to the song "I Will Survive": "I have all my life to live, and I have all my love to give."

I have the courage to go on: No matter how dark the day or long the night, I will survive. I have survived other hard times and I know others have also survived.

I believe in myself: There is always a *me* deep inside, capable of moving on. I can trust and have confidence that my deep self will see me through these difficult times. I can find others who believe in me just as I can believe in them.

I can overcome negative beliefs: In addition to reinforcing positive beliefs, it is vital to let go of, neutralize, or at least suspend negative beliefs about oneself and the world. Unfortunately, many of these negative beliefs are the product of a materialistic, mechanistic culture which is often reflected in our modern medical system which emphasizes pathology. I believe, however, health - not illness and disease - is our more usual condition.

The PACE Recovery Plan

1. Self-to-self: self-help, coping, healing

Recovery at your own pace

- a. Believing in one's capacity to recover through use of self-help manuals, tapes, and videos by people who have recovered, on topics such as coping with voices
- b. Dreaming dreams of what one most wants
- c. Developing one's own plans for exercise, diet, meditation, biofeedback, visualization, self-care
- d. Exploring self-expression through writing, music, arts, dance
- e. Cultivating a personal spirituality, philosophy, and or religion

2. Self-to-helper: personal assistance from people who believe in you

- a. Consumer-directed services: client-centered psychotherapy, self-directed rehabilitation
- b. Informed choice: medication and its alternatives
- c. Complementary medicine: acupuncture, herbs, massage etc.
- d. Advance directives and health care proxy: be well informed by making sure it is the c/s/x's own plan
- e. Collaborative record keeping: treatment planning/record keeping in full partnership with provider

- f. Supported work through a job coach, supported housing, supported education, supported parenting
- g. Compeer, Big Sister/Brother or other volunteer activities

3. Self-to-peer: intimates, friends, siblings

Recovery through membership in small groups

- a. Self-help groups, mutual support
- b. Warm lines – assisting or being assisted in times of distress
- c. Consumer-run social clubs
- d. Promoting human rights through advocacy
- e. Consumers working in the mental health system as providers, or through participating on advisory or governing boards

4. Self-to-the-greater-world

Recovery through community membership

- a. Groups and activities outside mental health system: churches, dance groups, bowling or other hobbies
- b. Being part of a work community through volunteering or through a part-time or full-time job
- c. Parenting
- d. Living in your own home or apartment

Frequently asked questions regarding PACE and recovery

What causes mental illness?

Despite over 100 years of research, there is no evidence that mental illness is primarily due to a specific chemical imbalance or genetic difference (Harrison, 1999). Social, psychological and cultural factors are just as important as biochemical ones. We are very complex beings, who exist on many levels at once. An over-emphasis on biological causation fragments and distorts existence, leaving people feeling they are no more than a collection of meaningless chemicals. This feeling interferes with recovery, which relies on taking an active role in running one's life and experiencing wholeness.

In contrast to the biological model, the empowerment model encourages people to take control of their lives on all levels. Rather than waiting for a professional to fix them, people see that their actions can be vital to their recovery. The more people learn to run their own lives, the more they feel whole. This gives them renewed hope, responsibility, and strength.

Do people still have symptoms after they recover from mental illness?

People who have recovered still go through periods of emotional distress, but these are no longer symptoms of mental illness because they have learned to retain control of their life. Hearing voices is a good example. Hearing voices was always thought to be a symptom of mental illness. Recently, however, Sandra Escher and Dr. Marius Romme's research (Romme and Escher, 1993) has shown that many people who were never labeled with mental illness are voice hearers. Furthermore, they have found that some people who have fully recovered from schizophrenia still occasionally hear voices. They found that the people who have recovered feel stronger than their voices, and have developed coping strategies. They can remain

involved in caring and supportive relationships despite the voices. It also seems necessary for these people to experience the voices as meaningful. People need to feel they can understand what the voices are telling them about their life. Then they can take steps to cope. These authors suggest that the chemical imbalance explanation offered by biological psychiatry is not helpful in recovery because it leaves no room for the person to learn to understand or to control their voices by their own thoughts or actions.

Research at NEC has reinforced these findings, as the following history illustrates: John was first labeled with severe mental illness when he was in college. He was very frightened by his thoughts and voices. He withdrew. He was afraid to tell people what he was experiencing. He was hospitalized several times and given heavy medication. Gradually through positive relationships, sensitive therapy, and meaningful work he recovered and came off his medication. Several years later the voices and negative thinking recurred. This time, however, he dealt with the distress at home, without medication. The difference was that through his previous experiences he learned that he could take steps to cope. He retained hope and did not slide into fear and despair. He felt that his voices helped him to understand himself better. Also he was not afraid to share the experience with his wife and coworkers. They were able to help him make the adjustments in his work and life to accommodate his temporary state of distress.

Is it possible to have recovered and still be taking medication?

Yes, because taking medication is not enough to define a person as mentally ill. Many people in society take psychiatric medications but are not considered mentally ill. The deciding factor is whether the person has learned to (re)gain control of their life and fills a valued social role. If medication is voluntarily used with full informed consent, as one coping tool among many others, it is not a sign of mental illness.

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*We are biological beings, to be sure,
but you can't put a person's life
experiences - fears, traumas,
thoughts, emotions, dreams, and
losses - under a microscope and
diagnose them and call it a disease.*

~ Laurie Ahern

*Mental illness is the loss of dreams,
not the loss of dopamine.*

~ Dan Fisher