THE RECOVERY PERSPECTIVE AND EVIDENCE-BASED PRACTICE FOR PEOPLE WITH SERIOUS MENTAL ILLNESS

A guideline developed for the Behavioral Health Recovery Management project
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Introduction

There is a great deal of interest in the concept of recovery from mental illness throughout the United States and internationally. There are some very specific reasons for this. In a review of recovery literature, Ralph (2000b) comments:

> There is a great deal of interest in recovery throughout the mental health community. Consumers[1] of mental health services who discover that there is such a concept are given hope that they can reach some level of normal life. Providers are realizing that to have their clients recover is to their advantage, not only so that the people they serve can enjoy better health, but also so that they can have enough staff and time to assist those who are coming into the system. Payers for mental health services (e.g. health maintenance organizations [HMOs], Medicaid) are most interested in being able to reduce services and costs. Funders of services (e.g. state mental health agencies, federal programs, legislators) want to see their dollars produce success. (p. 1)

At present, recovery from mental illness is not considered an "Evidence-Based Practice" because there have been no randomized, clinical trials with "proven" results. Yet, all of the above constituents (consumers, providers, payers, funders) are looking for definitions, information and studies which tell them more about recovery, what it is, how it takes place, and how it can be achieved. There is also a debate as to whether recovery is a process or an outcome – or perhaps both. Some state and local mental health systems are now implementing ways in which to assist clients in their recovery (Barton, 1998; Jacobson & Curtis, 2000).

Recovery requires a paradigm shift in our thinking as mental health researchers, administrators, program managers, direct service providers and consumers of mental health services. We must no longer think about people with mental illness as always being disabled. We must, first of all, see people who experience mental illness as human beings who can move on to better times in their lives. And yet – recovery does not necessarily mean "cure." It is a way of living in order to make the most out of life.

In this paper we include information about evidence of recovery and practices in recovery which are taking place in many parts of the nation. We also address the conflict or debate as to whether

recovery is or even should be considered an evidence-based practice. We conclude with recommendations for the further exploration of recovery from mental illness.

What is the Evidence?

There is a wealth of evidence that recovery does take place, that it can be theoretically described in model and narrative, that it can be taught, and that it can be practiced. There are also some preliminary efforts to measure recovery.

Personal Accounts

The first set of evidence is in personal accounts written by people who have experienced mental illness and recovery. These provide information about how the person recovered and what is important in maintaining his/her recovery. There are literally hundreds of accounts of personal experience with mental illness and recovery, both published and unpublished. Personal accounts are published regularly in peer-reviewed journals such as *Psychiatric Services, Psychiatric Rehabilitation Skills* and *Psychiatric Rehabilitation Journal.*

The following are examples of the information found in personal accounts.

> "Recovery is a process, a way of life, an attitude, and a way of approaching the day's challenges. It is not a perfectly linear process. At times our course is erratic and we falter, slide back, regroup and start again. The need is to meet the challenge of the disability and to re-establish a new and valued sense of integrity and purpose within and beyond the limits of the disability; the aspiration is to live, work, and love in a community in which one makes a significant contribution." (Deegan, 1988, p. 15)

> "One of the elements that makes recovery possible is the regaining of one's belief in oneself." (Chamberlin, 1997, p. 9)

> "Having some hope is crucial to recovery; none of us would strive if we believed it a futile effort . . . I believe that if we confront our illnesses with courage and struggle with our symptoms persistently, we can overcome our handicaps to live

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1 People who experience mental illness prefer being called by their name. We use consumer in this paper to depict people who are sad, who experience mood swings, who see or hear things that others do not see or hear, or have experienced terrible trauma.

independently, learn skills, and contribute to society, the society that has traditionally abandoned us." (Leete, 1989, p. 32)

"A recovery paradigm is each person's unique experience of their road to recovery . . . My recovery paradigm included my re-connection which included the following four key ingredients: connection, safety, hope, and acknowledgment of my spiritual self." (Long, 1994, p. 4)

"What there is now that is new is the beginning of trust that the bad times will pass and the underlying strength will prevail. What there is now is insight about how externals affect me and how to better manage myself in connection with outside factors. What there is now is acceptance I reinforce what I learn with an annual life review." (Caras, 1999, p 1)

"To return renewed with an enriched perspective of the human condition is the major benefit of recovery. To return at peace, with yourself, your experience, your world, and your God, is the major joy of recovery." (Granger, 1994, p. 10)

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

(1) **internal factors** – those factors which are within the consumer him/herself, such as the awakening, insight, and determination it takes to recover;
(2) **self-managed care** – an extension of the internal factors where consumers describe how they manage their own mental health and how they cope with the difficulties and barriers they face;
(3) **external factors** – those factors which include interconnectedness with others, the supports provided by family, friends, and professionals, and having people who believe that they can cope with and recover from their mental illness; and
(4) **empowerment** – "which is a combination of internal and external factors – where the internal strength is combined with interconnectedness to provide the self-help, advocacy, and caring about what happens to ourselves and to others." (Ralph, 2000a, p. 484)

Models

A second set of evidence is the development of models to provide a construct or a conceptual framework through descriptions, images, and definitions. These models have characteristics in common, but also bring different ideas to the concept and definition of recovery.

DeMasi and colleagues (1996) developed a well-being recovery model based on their review of the literature. The three areas of well-being proposed were: health (both physical and mental health), psychological, (self-esteem, hope, coping, and confidence), and social quality of life (economical and interpersonal). A Self-Help Survey, using a number of scales, was mailed to 956 individuals in New York State with 612 people who completed and returned the survey for a 64% return rate. Using confirmatory factor analysis the structure of the hypothesized model was tested and supported. The results indicate that recovery spans beyond the mental health system, is supported by a combination of support services, and emphasizes the importance of a partnership between clinician and client, and between traditional and alternative services.

The Empowerment Model of Recovery (Fisher & Ahern, 1999) was developed at the National Empowerment Center to emphasize the importance of social supports in the recovery process. When social supports are insufficient, it is difficult for people in emotional distress to maintain the major social role expected of them.

A Public Health Model for the Recovery of Adult Mental Health was developed by Dornan and colleagues (2000) and highlights hope as the central theme. Phases or characteristics of recovery threaded through the major concept of hope include the will to survive, awakening, action plan, self and shared determination, and leads to recovery. Recovery is defined "as the act of gaining and taking back hope, personal identity and abilities – from loss due to disorder, injury, or submission to powerlessness. It is also a taking back of trust in one's own thoughts and choices so as to restore mental, emotional, social and biological order. It may be lifelong, intermittent, or short-term." (p. 2)

A relational worldview model has roots in the American Indian tribal cultures and is also referred to as the Medicine Wheel. This model appears as a circle or sphere with four quadrants called context, mind, body, and spirit, which represent the four major forces or sets of factors that together must come into balance. "The relational worldview sees life in terms of harmonious relationships; health or wellness is achieved by maintaining balance among the many interrelating

factors in one's circle of life. Every event relates to all other events regardless of time, space, or physical existence. Health exists only when all elements are in balance or harmony." (Cross et al. 2000, p. 8)

The Recovery Advisory Group Recovery Model (Ralph et al. 1999) was developed by a group of consumer leaders through monthly teleconferences in which they discussed their own and others' recovery experiences. Recovery is defined through a number of stages: anguish, awareness, insight, action plan, determination to be well, and well-being/recovery. The path is not linear, and people may move back and forth among the various stages. The model indicates that recovery is both internal (within oneself) and external (interactions with others). External influences (e.g. family, friends, community, and mental health system) can support or deter recovery. The "meat" of this model is a grid, in which internal aspects (cognitive, emotional, spiritual and physical) and external aspects (activity, self-care, social relations and social supports) are described with a phrase or sentence in each of the stages of anguish, awareness, insight, action plan, determination to be well, and well-being/recovery.

Consumers often talk about their recovery working in a spiral. They may move back and forth between stages but may end up on a higher plane. In the field of addiction, Prochaska and colleagues (1992) developed a model based upon data that indicates a spiral four-step process of pre-contemplation, contemplation, preparation and action. In the pre-contemplation stage, there is no recognition of the problem or intention to change; in contemplation, the person is thinking about doing something about the problem; in preparation, there is an intention and action in dealing with the problem; and when a person modifies his/her behavior in order to overcome the problem, the step is called action.

A conceptual model of recovery was developed by Jacobson and Greenley (2001a) in concert with the State of Wisconsin's efforts toward developing a recovery-oriented mental health system (The Blue Ribbon Commission, 1997). In this model, "recovery refers both to internal conditions – the attitudes, experiences, and process of change of individuals who are recovering – and external conditions – the circumstances, events, policies, and practices that may facilitate recovery" (p. 482). Internal conditions include hope, healing, empowerment, and connection, while external conditions include human rights, a positive culture of healing, and recovery-oriented services.

Research Studies

A third set of evidence includes both definitional studies and outcome studies in recovery. Definitional studies attempt to answer the questions: “What is recovery?”, “How do people recover?” or “What is important in recovery?” They may be qualitative studies of published and unpublished personal narratives, analysis of interviews with a number of consumers or ratings of concepts important to recovery. Outcome studies view recovery as an end result – an outcome. There are efforts to find out how many people in the study recovered (as defined in the study). Some studies include aspects of both definitional and outcome studies.

Surveys of 71 consumers in Ohio and 180 in Maine were used to rate ten items of importance in their recovery (Ralph, 2000a). The top four responses were:

- The ability to have hope
- Trusting my own thoughts
- Enjoying the environment
- Feeling alert and alive

Ridgeway (2001) analyzed four early consumer recovery narratives (Lovejoy, 1982; Deegan, 1988; Leete, 1989; Unzicker, 1989) with a constant comparative qualitative method to find common themes. These themes are as follows:

Recovery is:

- The reawakening of hope after despair,
- Breaking through denial and achieving understanding and acceptance,
- Moving from withdrawal to engagement and active participation in life,
- Active coping rather than passive adjustment,
- Moving from alienation to a sense of meaning and purpose,
- A complex and nonlinear journey, and
- Not accomplished alone – the journey involves support and partnership.
- Recovery means no longer viewing oneself primarily as a person with a psychiatric disorder and reclaiming a positive sense of self.

In a dimensional analysis of 30 personal narratives, Jacobson (2001) describes four dimensions: recognizing the problem, transforming the self, reconciling the system, and reaching out to others. She also identifies explanatory models, which frame a person’s approach and attitudes about

recovery. These explanatory models are: biological, abuse or trauma, combination of biological and abuse, spiritual or philosophical, and political.

Smith (2000) interviewed 10 volunteers from a consumer operated service, and found the following major themes:

- Right kinds of medication
- A group of supportive people
- Meaningful activities
- A sense of control and independence
- A strong determination to maintain recovery
- A positive outlook on the present
- Optimism about the future

The *Well-Being Project* (Campbell & Schraiber, 1989) is a landmark effort in which mental health consumers conducted a multifaceted study to define and explore factors promoting or deterring the well-being of persons diagnosed with mental illness in California. Respondents were interviewed in psychiatric hospitals, skilled nursing facilities, residential treatment centers, drop-in centers, mutual support groups, and on the streets. Of the 331 clients who responded, 87% had been hospitalized; of the 53 family member respondents, 91% reported their relative had been hospitalized. Nearly 60% of the clients surveyed indicated they could always or most of the time recognize signs or symptoms that they are having psychological problems (i.e. insight) and almost half reported that they can always or most of the time take care of the problem before it becomes serious. The most favored coping and help-seeking practices of consumers were: writing down their thoughts or talking the problem out (50%); eat (52%); calling or seeing friends (52%); relaxing, meditating, taking walks or a hot bath (54%); and calling or going to see a mental health professional (62%).

The classic outcome study is that of the 32-year longitudinal study of patients from the Vermont State Psychiatric Hospital reported by Harding and colleagues (1987). Patients who had been hospitalized continuously for 6 years participated in a rehabilitation program and were released in a planned process with community supports in place. In the follow-back study, 262 (97%) of the original patients were traced. Thirty-four percent of the living people with a diagnosis of schizophrenia experienced full recovery in both psychiatric status and social functioning (i.e. no current signs or symptoms of any mental illness, no current medications, working, relating well to

family and friends, integrated into the community, and no indication of having been hospitalized for any kind of psychiatric problem). An additional 34 percent of the people were significantly improved in both areas.

A selection of patients hospitalized in Maine during the same period of time were matched to the Vermont cohort by age, sex, and diagnosis and outcomes were compared between the two groups (DeSisto et al. 1995). It was generally found that Vermont subjects were more productive, had fewer symptoms, and displayed better overall functioning and community adjustment. The rehabilitation program was considered the reason for this.

In an overview of World Health Organization (WHO) studies on schizophrenia, De Girolamo (1996) found that "independent from the setting and contrary to the beliefs held in the psychiatric field for decades, there is a remarkable percentage of patients who recover from the illness" (p. 224). In 27 major long-term follow-up studies (including Harding's) published between 1960 and 1991, the percent of patients clinically recovered ranged from a low of 6% to a high of 66%, with an average of 28% and a median of 26%. The percentage of patients who showed a social recovery ranges from a low of 17% to a high of 75%, with an average of 52% and a median value of 54%.

The role of social relationships in recovery was studied with 20 hospitalized patients by Breier and Strauss (1984). Initial interviews focused on obtaining information about each person's psychiatric problems and identifying relationships between these problems and work, friendships and family status. Information on social relationships was obtained through monthly interviews for one year. All of the patients described specific ways in which social relationships were beneficial to their recovery.

The importance of a sense of self was studied by Davidson and Strauss (1992) with 66 people initially hospitalized for severe mental illness, and followed over a two-to-three-year period with intensive interviews. Nearly half of the study participants improved on the Global Assessment Scale over the course of the study. Review of self-report data revealed four basic aspects of recovery and the reconstruction and development of the sense of self. These are:

(1) discovering the possibility of possessing a more active sense of self;
(2) taking stock of the strengths and weaknesses of this self and assessing possibilities for change;

(3) putting into action some aspects of the self and integrating the results of these actions as reflecting one's actual capabilities;
(4) using an enhanced sense of self to provide some degree of refuge from one's illness and the detrimental elements of one's social milieu (e.g. stigma) and to provide a resource with which to battle them. (p. 134)

The Consumer Leadership Education Program (LEP) prepares mental health consumers for leadership positions on community agency boards and committees (Bullock & colleagues, 2000). The curriculum design, developed in a participatory process with a consumer advisory group, includes three segments: (1) attitude and self-esteem; (2) group dynamics and group process; and (3) board/committee functions and policy development. Using wait-lists as control groups, pre-, post- and six-month follow-up assessments were conducted. Training participants reported significant improvement in their (1) ability to control negative and social symptoms of their illness, (2) social relationships, (3) personal care and vocational skills, and (4) personal power. There was also a trend toward improvement in overall attitude about recovery from mental illness, using the Recovery Attitude Questionnaire (Borkin et al. 1998).

The recovery process of incest survivors was studied through in-depth semistructured interviews focused on healing with 10 adult women (Godbey and Hutchison, 1996). Participants in this study described the resurrecting of the buried self as a complex, long and arduous process, but one that results in long-term satisfaction. They indicated that in order to accomplish this, they needed to work with a trusted therapist, have emotional support from family and friends, and most importantly, have a real commitment to healing.

Recovery Practices

Recovery practices are being developed rapidly from a diverse set of sources. They tend to fall into the categories of (1) how to recover, (2) how to maintain your recovery (or mental health), and (3) how to help others recover. Some practices include more than one of the above categories. It should be noted that the practices described here are only examples of what is available, and do not pretend to cover all recovery practices.

Recovery Education

Some of the "how to recover" information has been developed as educational material, in which consumers meet on a regular basis to learn about recovery concepts and discuss ways of

incorporating them into their own life. Often these groups or classes may also lead into the second category of "how to maintain your recovery." Knight (2000) summarizes:

> Recovery education programs have dual goals. The first is to provide information about the fact that recovery is possible, including how others have done it. The second is to provide experiences that facilitate the achievement of recovery-related attitudes, thoughts, and behaviors. (p. 4)

The first example is *The Recovery Workbook* (Spaniol, Koehler, & Hutchinson, 1994) and its companion *The Leader's Guide* (Spaniol, Koehler, & Hutchinson, 1994). These were developed at the Center for Psychiatric Rehabilitation at Boston University. Accompanying these is *The Experience of Recovery* (Spaniol & Koehler, 1994), a collection of first-person accounts of individual recovery experiences. The recovery education using these books, was planned to be led by 2 people, at least one of which is a person who has experienced mental illness, and who is well along in his/her own recovery. Group size is about 15 people, meeting once a week for two hours for 30 weeks. This may vary depending on the leadership and the participants in the group.

The specific goals of the workbook are:

1. To become aware of the recovery process;
2. To increase knowledge and control;
3. To become aware of the importance and nature of stress;
4. To enhance personal meaning;
5. To build personal support; and
6. To develop goals and a plan of action. (p. 3)

These materials have been used in a variety of settings, in both traditional mental health service settings and consumer operated settings. Recently, a new workbook has been added to these materials, *The Recovery Workbook II: Connectedness* (Spaniol, L., Bellingham, Cohen, Spaniol, S., 2002) and its accompanying *Leader's Guide* (Spaniol, L., & Spaniol, S. 2002). Topics in this workbook include: connecting with oneself, connecting with others, connecting with our environments, and connecting with a larger meaning or purpose.

The Wellness Recovery Action Plan (WRAP) was developed by Mary Ellen Copeland in 1997 with a group of people who were having a hard time with severe and troubling symptoms and behaviors, to the point they spent much time in hospital and day treatment programs. They spent several days working together to formulate this plan, and it has been used by hundreds of people since its inception.

> WRAP is a self-management and recovery system designed to maintain wellness, decrease symptoms, increase personal responsibility and improve quality of life. The self-designed plan teaches you how to keep yourself well, to identify and monitor your symptoms and to use simple, safe, personal skills, supports, and strategies to relieve these symptoms. WRAP can be used along with any other treatment scenario that you have chosen for yourself. (Copeland, 2002, p. 5)

Copeland is a recovery educator who has also experienced mental illness. She conducted a study with 120 people who struggled with depression and bipolar disorder, and used her findings to write her first book, *The Depression Workbook* (Copeland & colleagues, 1992). She has developed a number of other books and manuals (see the Resources section) and leads educational workshops. She also provides training for facilitators of recovery education programs, like the WRAP.

In the early 1990s, a needs assessment was done in Tennessee collaboratively by consumers with focus groups of consumers. The BRIDGES (Building Recovery of Individual Dreams and Goals through Education and Support) recovery education program grew out of this effort, with professionals and consumers invited from around the country to contribute to the development of a curriculum. It was piloted in three Tennessee locations, revised in response to early feedback, and used in 18 locations in 1996. (Knight, 2000; Tennessee Mental Health Consumers' Association [TMHCA], 1999). Since then it has been used in many more locations. Classes are 2 hours in length and held weekly for 15 weeks. Class leaders are always consumers, and work in groups of 3 – a leader/facilitator, an assistant to help individual participants, and a site coordinator to handle supplies and do errands. Following the course, leaders help class members to start peer support groups for participants to facilitate. Tennessee is using the BRIDGES educational materials as one site in the multisite study of Consumer Operated Services Programs, currently underway (funded by the U.S. Center for Mental Health Services of the Substance Abuse and Mental Health Services Administration). Other states have also adopted the BRIDGES program.

<u>Self-Managed Care</u>

Daniel Fisher (1998), a consumer psychiatrist and Executive Director of the National Empowerment Center, has coined the term "self-managed care." He defines it as follows:

> Self-managed care is consumer-directed, multi-level, strength-building planning to genuinely assist a person to gain a meaningful role in society. This planning is

> contrasted to maintenance-based treatment planning which by its nature is professionally directed to correct pathology. (p.37)

Consumer written literature is a good source of information about self-managed care, and how the author has found ways to manage his/her mental health. Houghton (1982) found that she had to analyze her own strengths and weaknesses to determine how to live a healthier way of life. "By learning about myself, my limits, and weaknesses and strengths, and by making changes in my way of life, I have been able to maintain my health and prevent a recurrence of mental illness" (p. 549). She identified what she needed to incorporate into her life, for example, good patterns of rest and sleep, exercise, diet, planning her day, setting a slower pace, keeping a calm atmosphere, and setting reasonable goals. She also found that mental stimulation and meaningful work were important in her life and health.

Knight (1993) advises that it is important not to panic when the signs of something unusual are in your mind. His strategies are as follows:

> Techniques which involve the use of one's attention can reduce the panic feeling. Being aware of one's body and immediate environment and the rhythm of one's breath will bring one back in contact with immediate surroundings and pull one out of the unhelpful things going on in one's mind. Ways of training one's attention include mindfulness meditation from Buddhism, the inner smile of Taoism, the Hezachist, or Jesus prayer in Christianity, and any number of words used in relaxation response – peace, love, or any other word the person likes. (p. 2)

Knight also advises that people should identify unhelpful feelings and thought patterns as if they are objects in the world. A sense of movement is helpful to keep oneself going. It is also helpful to face the anxiety, find out what the immediate threat is, and decide you can live through it.

Being in control is the way Deegan (1993) manages her life:

> To me recovery means I try to stay in the driver's seat of my life. I don't let my illness run me. Over the years I have worked hard to become an expert in my own self-care. Being in recovery means I don't just take medications . . . . Rather I use medications as part of my recovery process . . . . Over the years I have learned different ways of helping myself. Sometimes I use medications, therapy, self-help and mutual support groups, friends, my relationship with God, work, exercise,

> spending time in nature – all these measures help me remain whole and healthy, even though I have a disability. (p. 10)

Three strategies in illness self-management are discussed by Corrigan (2002), in a paper designed for this web series. He summarizes as follows:

> . . . motivational interviewing to establish a person's goals, psychoeducation to learn skills to accomplish these goals, and consumer-operated systems which provide communities where these goals can flourish. (p. 21)

Consumer Operated Services or Self-Help/Peer Support

Many consumers who are working on their recovery find that mutual support, self-help groups or consumer operated services are helpful to their recovery. "Self-help is based on the principle that people with a shared condition come together to help themselves and each other to cope, with the two-way interaction of giving and receiving help seen as therapeutic in itself" (Van Tosh, Ralph & Campbell, 2000, p. 391). Medvene (1986), in a review of self-help research studies, found that these studies show that quality of life is significantly improved by participants in self-help groups. It was also shown that medical care and hospitalization was reduced for people who participated in such support groups.

In his discussion of consumer operated services, Corrigan (2002) discusses various aspects of the belief system of consumer operated services which support recovery.

- Consumer operated services are strong supporters of the recovery process, in the belief "that consumers have the potential to accomplish any life goal that they choose to target . . . The kind of hope and energy of this perspective permeates the programs at consumer operated services." (p.19)
- The helper principle and the peer principle guide the belief system of consumer operated services. "The helper principle reflects the essential wisdom of mutual assistance; namely, program participants benefit not only from being helped by others . . . but also from helping peers (which substantiates the message that they are ordinary competent people and augments feelings of worth). The peer principle takes this idea one step further; participants have shared experiences that lead to similar values." (p.19)
- Recognition of therapeutic or helpful processes not found in traditional mental health services, such as creativity, humor, and spiritual growth. Opportunities for visual and

performance arts, self-humor – laughing at oneself or one's situation, and the acceptance and encouragement of spiritual growth are all part of the contributions of consumer operated services.

Self-Help/Peer Support takes many different forms. It may be as simple as one consumer linking up and providing mutual support and caring with another consumer. When organized with programs, space, or curriculum, it is generally considered to be Consumer Operated Services. Some examples are:

- Drop-In Center where there are staff who provide some activities and are supportive, and there is space to sit, read the paper or other materials, watch videos, or visit with each other. Peer support often happens in these settings both between staff and members or between members. (Elkanich, in press)
- Educational programs where people come together to learn about recovery, how to keep and maintain their mental health, or learn advocacy or other skills.
- Peer support programs which provide group activities with planned discussion and learning opportunities.

Recovery in the Mental Health System

Anthony (1993) introduced recovery as the guiding vision for the mental health system after reading and listening to consumers' personal accounts of their struggle through and recovery from mental illness. He traced the progress of the mental health system from deinstitutionalization through the establishment of community support and rehabilitation services, with recovery envisioned as the next step in the process. Anthony notes that while deinstitutionalization focused on new uses for buildings and facilities, the community support system was planned as a network of essential services to support persons with psychiatric disabilities, and the field of psychiatric rehabilitation emphasized treating the consequences of mental illness. However, recovery speaks about how recipients of service will live and choose the services they need and want. He emphasizes that service providers must be understanding and tolerant of the range of intense emotions experienced by consumers during recovery without diagnosing behavior as abnormal or pathological. The mental health system must provide the environment that stimulates and encourages recovery.

Person Level Direct Care

Some of the most important "players" to provide this environment in the mental health system are the people who provide direct care on a regular basis. The attitudes reflected in behavior are extremely important in enhancing or destroying recovery. One of these behaviors is the language we use when talking to people with psychiatric disabilities. It shows respect or disrespect for each other. Providers talk about "compliance" and "treatment resistant." Consumers talk about "choice" and "right to refuse" when the "treatment" seems counterproductive to what they feel, or the side effects are worse than the illness. When consumers and providers talk together, when they can see each other as equals, when they can talk about their individual needs and wants, when they can share their feelings of accomplishment and weakness, then they can gain perspectives from each other. Their lives, the system, and the program is enriched! (Ralph, 2001) These behaviors are best understood when they are described by people who have experienced them.

Attitudes and behavior that support recovery are described by Fisher (1997) in an article entitled: "Someone Who Believed In Them, Helped Them To Recover." A number of quotations from different people describe the helpful kinds of behavior that can assist people to recover. Some examples follow:

> One woman stated that there was a doctor who "believed in me. She never gave up. She was the only one who didn't give up as far as my being in the hospital."
>
> Another woman stated that for her it was a caring therapist. She said, "He was the first person I encountered out of the ordeal that actually had some sort of feeling. He was sympathetic at least and was understanding. He was really helping me out and motivating. Motivating me to keep on fighting, don't give up . . . Don't let them get their way, just keep on fighting."
>
> A nurse working with me reflected that the most important elements to her recovery were, "Having a mentor, a connection and a relationship . . . someone I made a strong connection to and they made one to me and they believed in me and I knew it . . . There was a knowing in their eyes that I saw that said I see you and I really believe in you. Someone that carried me. Somehow that encouraged me to not fall backwards." (p. 3)

Fisher (1997) also describes a worker in a residential service who has made a difference in a number of people's lives. He earns people's trust by listening and responding to their requests and working with them to accomplish their wishes. Staff indicate that when he walks into a room

everyone feels a sense of calm and peace, and yet he can be firm when he needs to. When he was asked what he felt was most important in his relationships with consumer/survivors, he said "I just accept them, the real person. Then they will present more and more of themselves to you." (p. 3)

In a focus on mental health nursing and recovery, Repper (2000) comments:

> Of paramount importance is the nurse's belief in the person's capacity to recover – whatever the manifestation and seriousness of these problems; willingness to be clear, honest and informative; desire to learn from each individual what they feel, think and want; and an ability to use this information in the manner most helpful to that person. (p. 583)

Beall (1992) describes a visit to a professional which she had resisted going to, but finally relented at the insistence of her husband and daughter.

> . . . Finally I went into the office and said that I was there under duress, that I did not believe there was any help for me. He replied that if he could not help me in short order, he was indeed the wrong person, and I should not come back . . . He listened and talked to me as if I were a real person and his equal. He told me he had treated several hundred people like me, but I was the only expert on my situation. My healing began then, at that moment. (p. 16)

One of the most revealing and vivid accounts of the effects of a professional's behavior is described by Tanya Ware (1995) in her discussion of the value of case management:

> . . . And then this woman from the mental health clinic came out to my home. That had never happened to me . . . She said she was my "case manager", that her name was Kaylene, and that she'd be back. And she did come back, and she didn't patronize me. Then the coolest thing happened. She drank my iced tea. Now I'm telling you, to drink iced tea made by a mental health patient you don't know very well takes either a great amount of courage or a great amount of confidence that the tea wasn't made with weird or dirty stuff in it. That's when I knew Kaylene was one smart cookie, because I've always made great tea. But what was more important was that she believed in me. Never in my life had anyone associated with the mental health profession believed in me. In fact, I was certain that mental health professionals were required to take at least two courses in patronization, and

at least three in “You can’t believe a word that comes out of a mentally ill mouth.” . . . Great things began happening . . . (p. 1231)

System Level

In expanding on his vision of recovery in the mental health system, Anthony (2000) has recommended some system level standards for recovery-oriented systems. He has identified recovery standards in the system level dimensions of design, evaluation, leadership, management, integration, comprehensiveness, consumer involvement, cultural relevance, advocacy, training, funding, and access. He indicates the following as essential services, describes them, and gives expected consumer outcome in a recovery-oriented system. It should be noted that some of these are not considered as services in current nonrecovery oriented mental health systems.

- Treatment – alleviating symptoms and distress – symptom relief
- Crisis intervention – controlling and resolving critical or dangerous problems – personal safety assured
- Case management – obtaining the services clients need and want – services accessed
- Rehabilitation – developing clients’ skills and supports related to clients’ goals – role functioning
- Enrichment – engaging clients in fulfilling and satisfying activities – self-development
- Rights protection – advocating to uphold one’s rights – equal opportunity
- Basic support – providing the people, places, and things clients need to survive (e.g. shelter, meals, health care) – personal survival assured
- Self-help – exercising a voice and a choice in one’s life – empowerment
- Wellness/prevention – promoting healthy lifestyles – health status improved (p. 161)

A number of states have included the word recovery or the concept of recovery in documents such as mission statements, guiding principles or descriptions of treatment programs. Some states are trying to incorporate recovery into the way mental health services are provided.

Ohio has been a leader in this effort. In 1993, the Ohio Department of Mental Health (ODMH) conducted a series of dialogues throughout Ohio and across the nation with consumers, family members and providers, including clinicians to explore the philosophy of recovery and to determine elements that contribute to the recovery process. In 1994, a Recovery Conference was followed with a discussion about the importance and use of recovery in the mental health system by the Community Support Program Advisory Committee, composed of clinicians, consumers, and

family members. They produced a report "The Recovery Concept: Implementation in the Mental Health System" (Beale & Lambric, 1995). The recommendations of this report were organized by the key themes of jobs, empowerment, stigma, peer support, family support, community involvement, access to resources, education, and clinical roles and relationships. Members of the Office of Consumer Services, collaborating with other members of ODMH and the community have continued to sponsor annual recovery conferences, recovery dialogues, and developed Consumer Quality Review Teams to assess and assure consumer satisfaction through voice and choice to improve quality outcomes and responsiveness of services. A result of this continued dialogue and emphasis on recovery is the development of the *Mental Health Recovery Process and Best Practices Model,* which is described in the publication *Emerging Best Practices in Mental Health Recovery* (Townsend et al. 1999).

In 1996, the Governor of Wisconsin authorized The Blue Ribbon Commission on Mental Health Care, whose purpose was to develop a long-term plan for mental health services in Wisconsin for children, adults, and elderly. The Blue Ribbon Commission adopted a concept of recovery, that is, the successful integration of a mental disorder into a consumer's life, as the key tenet of the redesigned mental health system. (The Blue Ribbon Commission, 1997, p.iii).[2] In a report prepared for the Commission, Jacobson (1998) conducted semistructured telephone interviews with key staff in 12 states, asking about how they operationalized and implemented recovery in their state mental health systems. Jacobson obtained her sample by identifying states that were purported to be leaders in this area, and was referred to others through a snowball sampling process. She indicated that states are at different stages in planning and implementation, and that approaches to incorporating recovery differ from state to state. "Some states seem to be repackaging their old service models (e.g. CSPs, supported education, rehabilitation services) using the recovery language; others are wholly re-inventing themselves" (p. 1).

Jacobson and Curtis (2000) summarize the findings from this study, in terms of the process taken by states to develop "recovery oriented" service systems and the areas or strategies selected to do this. The process is described as an effort to understand the concept and to determine its viability and value within clinical and financial constraints. The development of a vision statement is done through the establishment of a task force or work group that includes diverse stakeholders. Multiple sources of information are tapped to assist in the understanding of the concept and the

[2] NOTE: Most consumers who are thinking about the definition of recovery would not accept this definition.

development of a vision statement incorporating a working definition of recovery and makes recommendations to implement the principles identified.

Jacobson and Curtis (2000) comment:

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

Strategies to implement and operationalize recovery in the mental health system in those states that have moved beyond the service name changing stage, include:

> education, consumer and family involvement, support for consumer operated services, emphasis on relapse prevention and management, incorporation of crisis planning and advance directives, innovations in contracting and financing mechanisms, definition and measurement of outcomes, review and revision of key policies, and stigma reduction initiatives. (Jacobson & Curtis, 2000, p. 335)

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

State and federal initiatives to identify successful mental health services include recovery as one of the areas that must be addressed. Although specific recovery indicators have not been identified yet, there is great interest in finding and using measures of recovery that help the mental health system determine whether people with mental illness are improving in their quality of life.

A draft report of work done by the National Association of State Mental Health Program Directors (NASMHPD) Technical Workgroup on Performance Indicators (1998) includes Recovery/Personhood/Hope as one of the nearly 50 indicators for adults with serious mental

illness. This indicator is identified as “developmental” in that there are no identified measures for this as yet, but it is deemed important enough to be included, and to search for or develop some way of measuring this indicator.

State Indicator Pilot Grants were awarded by The Center for Mental Heath Services (CMHS) to 16 states in 1998 to pilot 32 selected performance indicators incorporated from the CMHS Five State Feasibility Study and the NASMHPD Framework of Mental Health Performance Indicators. A research team, working with a subgroup of these states, has conducted consumer focus groups in nine states with a common set of questions regarding what helps and what hinders their recovery. Focus group participant responses were qualitatively coded and summarized by category. The information in the resulting phase one research report (Onken, Dumont, Ridgway, Dornan, & Ralph, 2002) will be used to develop a set of recovery indicators.

Jacobson and Curtis (2000) conclude their article with very important thought provoking questions about recovery and the challenges faced by individuals and systems, as recovery is studied and attempts are made to implement and operationalize a recovery oriented system.

Much remains to be learned about recovery. Among the questions that must be answered:

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

- What barriers stand in the way of implementing a recovery orientation? What forces sustain the status quo?
- *Should* recovery be the foundational principle of the mental health system?

These start with problems of epistemology – how best to study and measure recovery. But they end in problems of politics and values – what is to be our society's approach to helping persons with psychiatric disabilities (Jacobson & Curtis, 2000, p. 339).

The Recovery Perspective and Evidence Based Practice: Is There a Conflict?

As the initiative to develop evidence based practice (EBP) has moved forward, there has been a vigorous discussion about whether, and to what degree, EBP and the recovery model are compatible. Evidence based practice relies on empirical evidence regarding the effectiveness of treatment and services for mental illness. What constitutes "evidence" depends on the framework used to evaluate practice and outcome. The framework for EBP in mental health is based primarily on the medical model.

In the view of some critics the medical model knowledge base of EBP is not compatible with the recovery model. When applied to mental health, the medical model focuses on disease control and reduction. Evidence of effectiveness is often measured in terms of reduced symptomatology or reduced service use. Usually not examined or measured are components at the core of recovery models, including hopefulness, quality of life, and empowerment.

The discussion of recovery and EBP breaks into several camps. In the view of some observers, EBP and recovery constitute irreconcilable world views and that EBP poses the threat of rolling back the advances made in understanding and promoting recovery (Anthony, 2001; Caras, 2001). EBP may diminish the legitimacy of recovery by controlling the "politics of evidence" (Fisher, 2002). Others with major responsibility for developing, vetting, and implementing EBP have promoted the importance of illness self-management within EBP and the need to better evaluate outcomes such as quality of life, housing, employment and other measures of community integration (Drake et al., 2001; Corrigan et al., 2001).

This discussion, much of it appearing in the journal *Psychiatric Services* during 2001, has been vigorous, sometimes contentious, and respectful. This is an important and still ongoing discussion that, we believe, will ultimately improve EBP in mental health. Below we describe some highlights

of this discussion and then recommend specific ways that the recovery model may better inform EBP.

Recovery and EBP: The Debate

Two luminary figures in consumer recovery have issued warnings about EBP. In her pioneering website for consumers (www.peoplewho.net), Sylvia Caras (2002) suggests that the recent emphasis in behavioral health on “evidence-based practice” and “best practices” may be a matter of the field "doth protest too much." Caras finds the evidence-based practice paradigm to be a framework that appears more concrete than it actually is.

> Refuting a paradigm which doesn't admit its assumptions and starts from existential statements is tough. Especially when today's behavioral health practices dismiss the evidence that would falsify the theories. Counter-examples from patient input are discounted; anecdote discarded. When we who are most directly affected tell our stories, recovery is dismissed as wrong diagnosis, and discomfort with medication is called non-compliance. (Caras, 2002)

Anthony (2001) cautions that EBP may serve to maintain traditional ways of delivering mental health services and fail to accept or validate newer, promising ways of delivering services. This happens because most existing mental health service systems were designed on the premise that persons with mental illness would either deteriorate or have their deterioration slowed down. EBP, predicated on published studies of the existing mental health service system, tends to use and validate outcome measures reflecting the traditional mental health system – relapse, recidivism, length of hospital stay, days spent in the community, ratings of psychiatric symptoms, or days employed. Such measures miss the mark of much of what we have learned is important for persons in coping with and recovering from psychiatric disability.

> Measures related to people's experience of progress (e.g., empowerment, well-being, physical health, recovery of meaningful roles) rather than relapse have become more relevant to questions of recovery. Simple counts of employment – yes or no, hospitalization – yes or no, are an enormous conceptual distance from what might be considered to be recovery outcomes. (p. 2)

Several articles and related commentary published in *Psychiatric Services* during 2001 bring into clear focus the fault lines between EBP and recovery models. Jacobson and Greeley (2001a), in their article, "What Is Recovery? A Conceptual Model and Explication" described the recovery

model developed to aid Wisconsin in moving towards its goal of a recovery-oriented mental health system. The authors present and attempt to link internal conditions experienced by individuals who are recovering – hope, healing, empowerment, connection – with external conditions (system and culture) that may help facilitate recovery – human rights, positive culture of healing, and recovery oriented services.

In the same issue of *Psychiatric Services*, a commentary on the Jacobson and Greeley article appears by Herbert Peyser (2001a) who acknowledges the usefulness of viewing persons with mental illness in a broader context than just their disease but warns that psychiatry must not forget that persons have a disease and that must be treated.

> How can we speak about “empowerment” and “collaboration” with the patient's reasonable self when it can be so subverted by the disease? Would that not really be empowering and collaborating with the disease process that imprisons the patient's self with hallucinations and delusions, rather than liberating the rationality and health of the patient within? (p. 487)

The authors acknowledge some truth in each other's position, but continue to point out the narrowness and miss-emphasis of the other's position in an exchange of letters to the editor (Jacobson & Greeley, 2001b; Peyser, 2001b).

Frese and colleagues (2001) explore the potential and offer suggestions for "Integrating Evidence-Based Practices and the Recovery Model.” The authors acknowledge the paternalism of the medical model that is antithetical to elements of recovery and the rejection by some consumers and advocates of the medical model and EBP. To find common ground where EBP and the recovery model may work together, it is important to consider the degree of disability of consumers. Persons most disabled by their mental illness tend to be represented in public policy and advocacy deliberations by the National Association for Mental Illness (NAMI). NAMI and other advocacy groups usually embrace the medical model in search of help for persons currently significantly disabled by their mental illness. Persons well along in their recovery can and are forceful and persuasive advocates for the recovery model and are critics of the medical model. The authors suggest that it may be consumers who are somewhere in between these two groups who may best be able to recognize the relative merits of recovery and EBP.

Moving Forward

Consumer advocacy and the recovery perspective began a quarter century ago in reaction to the failure of the mental health system to acknowledge that persons with severe mental illness could reclaim – or recover – the meaningful lives they had before the onset of their illness. Some consumers, particularly trauma survivors, feel they have never had a meaningful life, but do want to heal and begin living a "normal" life. Early advocacy efforts led to increased recognition by mental health professionals and policymakers of the role and importance of recovery. The Surgeon General's Report on Mental Health – charged with reviewing the best science-based knowledge of mental illness and ways to treat it – acknowledged a crucial role for recovery as part of mental health treatment.

Conceptually, then, the recovery perspective and evidence based practice are compatible and potentially have much to offer each other. To realize this potential, it is important for both groups to work together concretely and in "good faith." We offer the following recommendations for doing this.

1. With respect to recovery, evidence-based practice should be broadened to include "encouraging and promising," but not yet confirmed evidence. (Anthony 2001).

2. Empirical studies of recovery, its components, and their relation to traditional and consumer mental health services (process and outcome) should be funded. This funding should include studies where recovery is the major research objective and studies where traditional mental health services are the primary research focus and inclusion of recovery measures is required.

3. Recovery, its components, correlates, and outcomes should be assessed for different ethnic and cultural groups.

4. Recovery needs to be considered in the context of persons with co-occurring mental health and substance abuse issues. This involves reaching common ground on philosophical and conceptual differences that have tended to separate mental health and substance abuse services and moving forward on empirical studies.

5. Traditional measures of mental health treatment should be broadened to include recovery issues and perspectives. For example, studies of medication compliance should include side-effects, choice, and empowerment.

6. These recommendations must be supported by adequate funding. There is a real and ongoing danger that this funding will leak away as the field begins to deal with the challenges of fully funding EBP. |Funding barriers pose a major challenge in implementing EBP. There are three levels of barriers and associated costs: training of providers; developing adequate support infrastructure; and paying for EBP practices that are often not covered by Medicaid and other payers.| These barriers and costs apply to the study and implementation of recovery practices as well.

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Resources

Many recovery resources are available in printed materials and on the web. Although not an exhaustive list, below are several widely known web sites which may be accessed by consumers, family members, providers, researchers and others:

Advocacy Unlimited: Founded by Yvette Sangster, AU offers a model program in which consumers learn advocacy skills and networking in order to help themselves and others gain access to the services they need and want and by doing so, work to effect changes in mental health policy and services through grassroots community, social, and legislative action. Developed in Connecticut, AU also has a program in Boston, Massachusetts.

Contact info:

Advocacy Unlimited
300 Russell Road
Wethersfield, CT 06109

Phone: (860) 667-0460
Toll Free in Connecticut: 1-800-573-6929
Fax: (860) 667-2240

URL: http://www.mindlink.org/
Email: webmaster@mindlink.org

Awakenings Project: Envisioned by Patrick Corrigan, Ph.D at the University of Chicago's Center for Psychiatric Rehabilitation, with the goal to counteract stigma, the project offers art shows and a literary and visual art publication, the Awakenings Review which showcases consumer talent. Through this project the community is afforded opportunities for positive social interactions with mental health consumers. Robert Lundin serves as the Dissemination Coordinator and Editor.

Contact info:

University of Chicago
Center for Psychiatric Rehabilitation
7230 Arbor Drive
Tinley Park, IL 60477

Phone: (708) 614-4770
Fax: (708) 614-4780

URL: http://www.ucpsychrehab.org/programs/awakenings/
Email: postmaster@ucpsychrehab.org

Boston University's Center for Psychiatric Rehabilitation: Information is available on how to register for trainings to learn and teach recovery techniques, how to sign up on-line to receive the Mental Health and Rehabilitation eCast and how to order printed materials such as Leroy Spaniol's Recovery Workbook.

Contact info:

Center for Psychiatric Rehabilitation
Boston University
940 Commonwealth Avenue West
Boston, MA 02215

Phone: (617) 353-3549
Fax: (617) 353-7700

URL: http://www.bu.edu/cpr/

Consumer Organization and Networking Technical Assistance Center (CONTAC): Contac is a national technical assistance service center providing resources for consumers/survivors/ex-patients and consumer-run organizations across the United States. Developed using research on the best and most successful consumer programs among other research, it promotes the importance of self-help, recovery, empowerment, and the development of management and leadership skills by consumers across the United States.

Contact info:

CONTAC
P.O. Box 11000
Charleston, WV 25339

Phone: 1-888-825-Tech or (304) 346-9992
Fax: (304) 345-7303

URL: http://www.contac.org/
Email: USACONTAC@Contac.org

Mary Ellen Copeland: Information includes The Wellness Recovery Action Plan (WRAP), one of the most utilized consumer-directed guides on how to recover. Instructions are also available on how to order her books and how to register for training sessions to become qualified to teach using her philosophy and methods. Her newsletter is available on-line or one can sign up to have it sent electronically or by mail.

Contact info:

Mary Ellen Copeland, MS, MA
P.O. Box 301
West Dummerston, VT 05357

Phone: (802) 254-2092
Fax: (802) 257-7499

URL: http://www.mentalhealthrecovery.com/
Email: copeland@mentalhealthrecovery.com

Mental Health Client Action Network (MHCAN): The Mental Health Client Action Network of Santa Cruz County is a consumer-run agency that works to provide mutual support and networking, advocacy, and education to the public to confront stigma and help consumers restore their dignity and self-respect.

Contact info:

MHCAN
1051 Cayuga Street
Santa Cruz, CA 95062

Phone: (831)469-0462
URL: http://www.mhcan.org/
Email: mail@mhcan.org

The Mental Illness Education Project: Lists books and videos among other resources which many have found helpful in the recovery process.

Contact info:

The Mental Illness Education Project, Inc.
P.O. Box 470813
Brookline Village, MA 02447

Phone: (617) 562-1111

URL: http://www.miepvideos.org/booklist.html
Email: info@miepvideos.org

National Empowerment Center: A consumer/survivor/expatient-led organization offering resources including a newsletter and information on an alternative to the P/ACT programs called PACE, Personal Assistance in Community Existence.

Contact info:

The National Empowerment Center
599 Canal Street
Lawrence, MA 01840

Phone: 1-800-POWER2U or 1-800-769-3728
(Outside the U.S.) +978-685-1518
(Fax) +978-681-6426
(TTY/TTD) 1-800-TTY-POWER or 1-800-889-7693

URL: http://www.power2u.org/

National Mental Health Consumers' Self-Help Clearinghouse: The Self-Help Clearinghouse is a national consumer-run technical assistance center which connects individuals to self-help and advocacy resources. Expertise is offered to self-help groups and other peer-run services for mental health consumers, and those interested in the consumer/survivor/ex-patient movement.

Contact info:

National Mental Health Self-help Clearinghouse
1211 Chestnut Street, Suite 1207
Philadelphia, PA 19107

Phone: 1-800-553-4KEY [4539] or (215) 751-1810
Fax: (215) 636-6312

URL: http://mhselfhelp.org
Email: info@mhselfhelp.org

Peoplewho: Resources for "people who experience moods swings, fear, voices, and visions" developed and maintained by Sylvia Caras, Ph.D. A number of electronic lists are offered for people who would like to share experiences with others in on-line forums.

Contact info:

People Who
146 Chrystal Terrace 5
Santa Cruz, CA 95060-3654

URL: http://www.peoplewho.net
Email: info@peoplewho.org

Recovery Inc.: In existence for 65 years, Recovery Inc. is a self-help program based on the work of the late psychiatrist, Dr. Abraham Low, who believed that people diagnosed with mental illness could take an active role in their own care.

Contact info:

Recovery, Inc. International Headquarters
802 N. Dearborn Street
Chicago, IL 60610

Phone: (312) 337-5661
Fax: (312) 337-5756

URL: http://www.recovery-inc.com/
Email: inquiries@recovery-inc.org

Zangmo Blue Thundercloud: Personal essays of recovery, advocacy and spiritual guidance offering hope and inspiration by Sally Clay, a leading member of the consumer movement.

URL: http://home.earthlink.net/~sallyclay/essays.html
Email: sallyclay@earthlink.net

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