

Recovery as a Journey of the Heart

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I would like to thank you for this opportunity to speak with you today. I am especially pleased to be speaking to so many faculty and field supervisors. Your task is very important. You are teaching students who will become tomorrow's mental health professionals. The message I would like to bring you today is that it is not enough to merely teach them facts and figures and knowledge. We must also help students to seek wisdom.

There is a difference between knowledge and wisdom. The etymological root of the word knowledge comes from the Middle English, "to recognize". And indeed students in the various mental health related disciplines are required to recognize and to master a specific field of knowledge. They are required to know how to conduct empirical inquiry, to formulate findings, to contribute to theoretical models, to learn clinical skills, etc. However students are not required to seek wisdom. Wisdom comes from the Greek *eidos* and *idein* which means "to see the form of essence" of that which is. Thus most students emerge from their studies full of knowledge or the ability to recognize things, but they lack wisdom or the ability to see the form or essence of that which is.

For example, when we teach our students about the heart we teach them that the heart is a pump; a type of organic machine with valves and chambers. And indeed, in time they

learn to recognize the anatomical heart in all its detail. After successfully passing their final anatomy exam we say, "This student knows about the heart". But in wisdom we would have to doubt this statement.

Wisdom would seek the form or essence of the heart. In wisdom we would see that the anatomical heart which we have given our students to study is nobody's heart. It is a heart that could belong to anybody and therefore it belongs to no-body. Wisdom would have us understand that there is another heart. There is a heart that we know about long before we are taught that the heart is a pump. I am speaking here of the heart that can break; the heart that grows weary; the hardened heart; the heartless one; the cold heart; the heart that aches; the heart that stands still; the heart that leaps with joy; and the one who has lost heart. Wisdom demands that we teach students of the human sciences about the essence of this heart. The human heart. Not the pump that beats in any - body but the one that lives in my - body and your -body.

In a similar fashion we pass on knowledge about mental illness. Students emerge from school with knowledge about neurotransmitters and schizophrenics and bi-polars and borderlines and multiples and OCD's. They become experts in recognizing illness and disease. But this is where we so often fail them. We fail them because we have not taught them to seek wisdom - to move beyond mere recognition in order to seek the essence of what is. We have failed to teach them to reverence the human being who exists prior to and in spite of the diagnosis we have placed upon them. Just as the generic, anatomical heart does not exist, neither does "the schizophrenic" or "the multiple" or the "bi-polar" exist outside of a generic textbook. What exists, in the truly existential sense, is not an illness or disease. What exists is a human being and wisdom demands that we see and reverence this human being before all else. Wisdom demands that we whole heartedly enter into a relationship with human beings in order to understand them and their experience. Only then are we able to help in a way that is experienced as helpful.

Those of us who have been labeled with mental illness are first and foremost human beings. We are more than the sum of the electro-chemical activity of our brain. Our hearts are not merely pumps. Our hearts are as real and as vulnerable and valuable as yours are. We are people. We are people who have experienced great distress and who face the challenge of recovery.

The concept of recovery is rooted in the simple yet profound realization that people who have been diagnosed with mental illness are human beings. Like a pebble tossed into the center of a still pool, this simple fact radiates in ever larger ripples until every corner of the academic and applied mental health science and clinical practice are effected. Those of us who have been diagnosed are not objects to be acted upon. We are fully human subjects who can act and in acting, change our situation. We are human beings and we can speak for ourselves. We have become self-determining. We can take a stand toward what is distressing to us and need not be passive victims of an illness. We can become experts in our own journey of recovery.

The goal of recovery is not to get mainstreamed. We don't want to be mainstreamed. We say let the mainstream become a wide stream that has room for all of us and leaves no one stranded on the fringes.

The goal of the recovery process is not to become normal. The goal is to embrace our human vocation of becoming more deeply, more fully human. The goal is not normalization. The goal is to become the unique, awesome, never to be repeated human being that we are called to be. The philosopher Martin Heidegger said that to be human means to be a question in search of an answer. Those of us who have been labeled with mental illness are not de facto excused from this most fundamental task of becoming human. In fact because many of us have experienced our lives and dreams shattering in the wake of mental illness, one of the most essential challenges that faces us is to ask, "who can I become and why should I say 'yes' to life?"

To be human means to be a question in search of an answer. However, many of us who have been psychiatrically labeled have received powerful messages from professionals who in effect tell us that by virtue of our diagnosis the question of our being has already been answered and our futures are already sealed. For instance I can remember such a time during my third hospitalization. I was eighteen years old. I asked the psychiatrist I was working with, "What's wrong with me?". He said, "You have a disease called chronic schizophrenia. It is a disease that is like diabetes. If you take medications for the rest of your life and avoid stress, then maybe you can cope." And as he spoke these words I could feel the weight of them crushing my already fragile hopes and dreams and aspirations for my life. Even some 22 years later those words still echo like a haunting memory that does not fade.

Today I understand why this experience was so damaging to me. In essence the psychiatrist was telling me that my life, by virtue of being labeled with schizophrenia, was already a closed book. He was saying that my future had already been written. The goals and dreams that I aspired to were mere fantasies according to his prognosis of doom. When the future has been closed off in this way then the present loses its orientation and becomes nothing but a succession of unrelated moments. Today I know that this psychiatrist had little wisdom at that time. He merely had some knowledge and recognized me as "the schizophrenic" who had been handed down through the generations by Kraepelin and Bleuler. He did not see me. He saw an illness. We must urge our students to seek wisdom, to move beyond mere recognition of illness and to whole-heartedly encounter the human being who comes for help. It is imperative that we teach students that relationship is the most powerful tool they have in working with people.

Beyond the goals of recovery, there is the question of the process of recovery. How does one enter into the journey of recovery? Today I would like to begin a conceptualization of recovery as a journey of the heart. We will begin in that place where many people find themselves; in that place of being hard of heart and not caring anymore.

Prior to becoming active participants in our own recovery process, many of us find ourselves in a time of great apathy and indifference. It is a time of having a hardened heart. Of not caring anymore. It is a time when we feel ourselves to be among the living dead: alone, abandoned and adrift on a dead and silent sea without course or bearing. If I turn my gaze back I can see myself at seventeen years old, diagnosed with chronic schizophrenia, drugged on Haldol and sitting in a chair. As I conjure the image the first thing I can see are the girls yellow, nicotine stained fingers. I can see her shuffled, stiff, drugged walk. Her eyes do not dance. The dancer has collapsed and her eyes are dark and they stare endlessly into nowhere.

People come and people go. People urge her to do things to help herself but her heart is hard and she cares about nothing except sleeping, sitting and smoking cigarettes. Her day consists of this: At eight in the morning she forces herself out of bed. In a drugged haze she sits in a chair, the same chair every day. She begins smoking cigarettes. Cigarette after cigarette. Cigarettes mark the passing of time. Cigarettes are proof that time is passing and that fact, at least, is a relief. From 9 a.m. to noon she sits and smokes and stares. Then she has lunch. At 1 p.m. she goes back to bed to sleep until 3 p.m. At that time she returns to the chair and sits and smokes and stares. Then she has dinner. Then she returns to the chair at 6 p.m. Finally it is 8 o'clock in the evening, the long awaited hour, the time to go back to bed and to collapse into a drugged and dreamless sleep. This scenario unfolds the next day and the next day and then the next, until the months pass by in numbing succession, marked only by the nextcigarette and the next....

During this time people would try to motivate me. I remember people trying to make me participate in food shopping on Wednesday or to help bake bread or to go on a boat ride. But nothing anyone did touched me or moved me or mattered to me. I had given up. Giving up was a solution for me. The fact that I was "unmotivated" was seen as a problem by the people who worked with me. But for me, giving up was not a problem, it was a solution. It was a solution because it protected me from wanting anything. If I didn't want anything, then it couldn't be taken away. If I didn't try, then I wouldn't have to undergo another failure. If I didn't care, then nothing could hurt me again. My heart became

hardened. The springs came and went and I didn't care. Holidays came and went and I didn't care. My friends went off to college and started new lives and I didn't care. I remember sitting and smoking and saying almost nothing. And as soon as the clock struck 8, I remember interrupting my friend in mid-sentence and telling her to go home because I was going to bed. Without even saying good-bye I headed for my bed. My heart was hard. I didn't care about anything.

I trust that the picture I am painting here is familiar to many of us. We recognize this picture of apathy, withdrawal, isolation, and lack of motivation. But if we go beyond mere recognition in search of wisdom we must dig deeper. What is this apathy, indifference, hardness of heart which keeps so many people in a mode of survival and prevents them from actively entering into their own journey of recovery? Is it merely the negative symptoms of schizophrenia? I think not. I believe that becoming hard of heart and not caring anymore is a strategy that desperate people who are at the brink of losing hope, adopt in order to remain alive.

Hope is not just a nice sounding euphemism. Hope and biological life are inextricably intertwined. Martin Seligman's (1975) work in the field of learned helplessness offers us great insight into the chiasmic intertwining of hope and biological life. He sights two examples. The first is a published report by Dr. H.M. Lefcourt (1973):

"This writer witnessed one such case of death due to a loss of will within a psychiatric hospital. A female patient who had remained in a mute state for nearly 10 years was shifted to a different floor of her building along with her floor mates, while her unit was being redecorated. The third floor of this psychiatric unit where the patient in question had been living was known among the patients as the chronic, hopeless floor. In contrast, the first floor was most commonly occupied by patients who held privileges, including the freedom to come and go on the hospital grounds and to the surrounding streets. In short, the first floor was an exit ward from which patients could anticipate discharge fairly rapidly. All patients who were temporarily moved from the third floor were given medical examinations prior to the move, and the patient in question was judged to be in excellent

medical health though still mute and withdrawn. Shortly after moving to the first floor, this chronic psychiatric patient surprised the ward staff by becoming socially responsive such that within a two-week period she ceased being mute and was actually becoming gregarious. As fate would have it, the redecoration of the third-floor unit was soon completed and all previous residents were returned to it. Within a week after she had been returned to the 'hopeless' unit, this patient...collapsed and died. The subsequent autopsy revealed no pathology of note and it was whimsically suggested at the time that the patient had died of despair." (p. 182-183)

The second example is that of an army medical officer named Major F. Harold Kushner. Major Kushner was shot down over North Vietnam and he was interned in a prisoner of war camp from 1968-1973. Here is how Dr. Seligman relates the story:

"When Major Kushner arrived at First Camp in January 1968, Robert has already been captive for two years. He was a rugged and intelligent corporal from a crack marine unit, austere, stoic, and oblivious to pain and suffering. He was 24 years old...Like the rest of the men, he was down to a weight of ninety pounds and was forced to make long, shoeless treks daily with ninety pounds of manioc root on his back. He never griped...Despite malnutrition and terrible skin disease, he remained in very good physical and mental health. The cause of his relatively fine shape was clear to (Major) Kushner. Robert was convinced that he would soon be released. The Viet Cong had made it a practice to release, as examples, a few men who had co-operated with them...Robert had done so, and the camp commander had indicated that he was next in line for release, to come in six months...

The (designated) month came and went, and (Robert) began to sense a change in the guards' attitude toward him. Finally it dawned on him that he had been deceived - that he wasn't going to be released. He stopped working and showed signs of severe depression: he refused food and lay on his bed in a fetal position, sucking his thumb. His fellow prisoners tried to bring him around. They hugged him, babied him, and when this didn't work, tried to bring him out of his stupor with their fists. He defecated and urinated

in his bed. After a few weeks, it was apparent to Kushner that Robert was moribund: although otherwise his gross physical shape was still better than most of the others, he was dusky and cyanotic. In the early hours of a November morning he lay dying in Kushner's arms. For the first time in days his eyes focused and he spoke: 'Doc, Post Office Box 161, Texarkana, Texas. Mom, Dad, I love you very much...' Within seconds, he was dead." (p. 168)

Seligman (1975, p.168) goes on to comment: "Hope of release sustained Robert. When he gave up hope, when he believed that all his efforts had failed and would continue to fail, he died. Can a psychological state be lethal? I believe it can. When animals and men learn that their actions are futile and that there is no hope, they become more susceptible to death. Conversely, the belief in control over the environment can prolong life."

To paraphrase I would say that when those of us with psychiatric disabilities come to believe that all of our efforts are futile: when we experience that we have no control over our environment; when nothing we do seems to matter or to make the situation better; when we follow the treatment teams instructions and achieve their treatment goals for us and still no placement opens up in the community for us; when staff decide where we will live, with whom we will live; under what rules we will live, how we will spend our money, if we will be allowed to spend our money, when we will have to leave the group home and at what time we will be allowed back into it, then a deep sense of hopelessness, of despair begins to settle over the human heart. And in an effort to avoid the biologically disastrous effects of profound hopelessness, people with psychiatric disabilities do what other people do. We grow hard of heart and attempt to stop caring. It is safer to become helpless than to become hopeless.

Of course, the great danger is that staff will fail to recognize the intensity of the existential struggle that the person who is hard of heart is struggling with. The danger is that the staff will simply say, "Oh, this person just has a lot of negative signs and symptoms and

that's a poor prognosis and we mustn't expect much from this person". Or staff may become judgmental and dismiss us as simply being lazy and unmotivated. Or the staff may succumb to their own despair and simply write us off as being "low functioning".

It is imperative that the instructors and field trainers of the next generation of mental health professionals help today's students to avoid these pitfalls. It is imperative that students be helped to understand that being hard hearted and not caring are highly motivated, adaptive strategies used by desperate people who are at great risk of losing hope. We must help students understand and empathize with the deep existential struggle that is at the heart of this dark night of despair.

There are a number of things I tell students about how to work with people who appear to be hard of heart, apathetic and unmotivated. First I help the student understand the behavior in terms of its existential significance. I want the student to grasp the magnitude of what it is they are asking a person to risk when they ask them to start to care about something again. I want them to understand that under the hardened heart lies the breaking heart. How much suffering, how much loss can a human heart hold before it breaks? It is not a crazy thing to try to protect such a vulnerable heart. Students must be helped to honor the strategy of giving up and to understand that perhaps that person shall never risk again. In any case, it is only the person whom we are trying to help who has the power to take the risk, to care about something - something as simple perhaps as caring enough to put a poster on their bedroom wall, or caring enough to wear some new clothes or to try a job placement. These may seem like small things but if we understand their full existential significance, such acts are small steps towards caring, toward admitting that I just might want to participate in the human community again.

Secondly, I ask students to suspend their perception of people as chronic mental patients and to try to see the individual as a hero. I ask them, could you have survived what this individual has survived? Perhaps this individual has done what you could not do. Perhaps they are not weak and fragile sick people. Perhaps those of us with psychiatric disabilities are incredibly strong and have fiercely tenacious spirits. Could you live on \$530 dollars a

month and cope with a disability at the same time? If a student can momentarily drop out of their distanced professional posture and in true humility come to see a person with a psychiatric disability as a hero who has survived, then I say there is a good prognosis for that student. That student has a chance of being human hearted while working in the human services and this is no small accomplishment.

Finally, I try to help students understand that although they do not have the power to change or motivate the person with a psychiatric disability who is hard of heart, they do have the power to change the environment, including the human interactive environment, in which that person is surviving. When working with a person with a psychiatric disability who is hard of heart, who has given up and who is motivated not to care anymore, we must understand that this is a person who feels they have no power. They experience all the power to be in the hands of others. They experience what psychologists call an external loss of control. For such people it is imperative to create an environment in which there are choices to be made. I am speaking here, not of forced choice such as either you take your medications or you go back to the hospital - (this is little more than coercion), but of real choices. I am speaking here of all types of choices, from "small concerns" such as what flavor ice cream you want, to what coffee shop you want to go to, to what kind of vocational goals you might want to pursue, etc.

The person with a hardened heart will reject, reject again these invitations to choose. However the staff must not fall into despair, feel like their efforts are futile, grow hard of heart and stop caring themselves. If they do this then they are doing exactly what the person with a psychiatric disability is doing. Staff must avoid this trap. They must do what the person cannot yet do. Staff must role model hope and continue to offer options and choices even if they are rejected over and over again.

Additionally, environments must include opportunities for people to have accurate information. Information is power and information sharing is power sharing. People who feel powerless can increase their sense of self-efficacy by having access to information. People who feel powerless also feel that what they say does not matter. Taking the time

to listen to people and to help them find their own unique voice is important. Having a voice in developing rules as well as having a say in the hiring and evaluation of staff are important ways of exercising a voice which for too long has been silenced. Finally, it is important to have other people with psychiatric disabilities working as paid staff.

Role models provide hope that maybe I, too, can break out of this hardened heart and begin to care again. People who are defending themselves against the possibly lethal effects of profound hopelessness must see that there is a way out and that actions they take can inch them ever closer to their desired goal. They need to see that the quality of life can get better for people who have been similarly diagnosed. They need to see that there are opportunities for improving their situation. That is why hiring people with psychiatric disabilities as mental health professionals and staff is so important. It is also why exposure to peer support, self help and mutual support are so important.

Choice, options, information, role models, being heard, developing and exercising a voice, opportunities for bettering one's life: these are the features of a human interactive environment which support the transition from not caring to caring, from surviving to becoming an active participant in one's own recovery process. Creating such environments are the skills which tomorrow's mental health professionals must master.

As for myself, I cannot remember a specific moment when I turned that corner from surviving to becoming an active participant in my own recovery process. My efforts to protect my breaking heart by becoming hard of heart and not caring about anything lasted for a long time. One thing I can recall is that the people around me did not did not give up on me. They kept inviting me to do things. I remember one day, for no particular reason, saying "yes" to helping with food shopping. All I would do was push the cart. But it was a beginning. And truly, it was through small steps like these that I slowly began to discover that I could take a stand toward what was distressing to me.

I know that anger, especially angry indignation played a big role in that transition. When that psychiatrist told me the best I could hope for was to take my medications, avoid stress and cope, I became enraged. (However, I was not smart enough to keep my angry

indignation to myself because the #1 rule is never get enraged in a psychiatrist's office if you're being labeled with chronic schizophrenia!) I also remember that just after that visit I made up my mind to become "a doctor". I was so outraged at the things that had been done to me against my will in the hospital as well as the things I saw happen to other people, that I decided that I wanted to get a powerful degree and have enough credentials to run a healing place myself. In effect I had a survivor mission that I felt passionately about.

I was also careful not to share my newfound aspiration with anyone. Imagine what my psychiatrist would have said to me if I had announced at age 18, having virtually flunked out of high school, with a combined GRE score of under 800, with a diagnosis of chronic schizophrenia, that I was planning on getting my Ph.D. in clinical psychology. "Delusions of Grandeur!" But in essence that is precisely what I did. Starting with one course in English Composition at the local community college I slowly made my way. Dragging my textbooks into the mental hospital with me or trying to read with double vision due to Prolixin, I inched my way forward. I had a strong spirituality that really helped. I had a strong therapeutic alliance with a psychotherapist. I lived with latter-day-hippies who had tolerance for lots of weird behavior including my psychotic episodes. After some experimenting in my early teens, I somehow intuited that drugs and alcohol were bad news for me and I did not use them even though the people around me did. In retrospect I know this was a wise decision. I read books about healing and psychopathology and personality theory in an effort to understand myself and my situation. I was always trying new ways of coping with symptoms including my relentless auditory hallucinations. And perhaps most importantly of all, when I got out of bed in the morning I always knew the reason why - I had a purpose in life, I had been called, I had a vocation and I kept saying yes to it. Even in the present I must make a daily affirmation of my vocation in order to keep going. The temptation to give up is still strong sometimes.

My journey of recovery is still ongoing. I still struggle with distress, grieve the losses that I have sustained, and eventually got involved in therapy to work through a history of child abuse. I am also involved in self-help and mutual support. But now I have grown beyond

the role of being a “consumer”. What matters to me most is that I am living a life that feels whole and valuable. I am surrounded by people I love and who love me. I am making a valuable contribution to my world.

There is more to the recovery process than simply recovering from mental illness. We must also recover from the effects of poverty and second class citizenship. We must learn to raise our consciousness and find our collective pride in order to overcome internalized stigma. Finally, many of us emerge from mental health treatment settings with traumatic stress disorders related to having sustained or witnessed physical, sexual and/or emotional abuse at the hands of staff. As one long term veteran of mental health services wrote: "The stuff I've been through was like a nightmare. Sometimes I go back into the nightmare. I cry every night about it. Remembering it is like being in the nightmare again...Sometimes I scream at night because I dream about the hospital I was raped in or some other hospital I've been in." (LaLime, 1990). Sometimes recovering from mental illness is the easy part. Recovering from these deep wounds to the human heart takes longer.

Recovery does not mean "cure". It does not mean stabilization or maintenance. Rather recovery is an attitude, a stance, and a way of approaching the day's challenges. It is a self-directed process of reclaiming meaning and purpose in life. It is a process that is marked by human resilience in the face of adversity. It is not a perfectly linear journey. There are time of rapid gains and disappointing setbacks. There are times of just living, just staying quiet, resting and regrouping. Each person's journey of recovery is unique. Each person must find what works for them. This means that we must have the opportunity to try and to fail and to try again. In order to support the recovery process mental health professionals must not rob us of the opportunity to fail. Professionals must embrace the concept of the dignity of risk and the right to failure if they are to be supportive of us.

In closing I would like to add that all around the world people who have been Psychiatrically labeled are organizing. We are organizing on the local, statewide, national

and international level. We are developing a collective voice and are fighting to overcome oppression, poverty, discrimination, and stigma. We are saying "no" to second class health care, poor or non-existent housing, and to the indignities that so often come with psychiatric hospitalizations including the barbaric use of restraint and seclusion. We are sitting at the table in dialogue with service providers and policy makers to find alternatives to involuntary treatment. We are joining with other disability groups to form a broad coalition of 40 million Americans with disabilities to achieve equity in healthcare, support services and entitlements.

We are also beginning to define our experiences in our own terms and to educate mental health professionals about our experience and what helps. We are beginning to discover, recover and celebrate our collective heritage through the collection and archiving of consumer oral histories and other efforts to reclaim our collective history. Like other socially devalued groups the time has come for people with psychiatric disabilities to reclaim our history and tell it in our own words.

A new age is upon us. We must help the students of today to understand that people with psychiatric disabilities are human beings with human hearts. Our hearts are as real and as vulnerable and as valuable as yours are. Understanding that people with psychiatric disabilities are first and foremost people who are in-process, growing and changing is the cornerstone of understanding the concept of recovery. We must not let our hearts grow hard and callused toward people with psychiatric disabilities. Our role is not to judge who will and will not recover. Our job is to create environments in which opportunities for recovery and empowerment exist. Our job is to establish strong, supportive relationships with those we work with. And perhaps most of all, our greatest challenge is to find a way to refuse to be dehumanized in the age of managed profit, and to be bold and brave and daring enough to remain human hearted while working in the human services.

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