Recovery and the Conspiracy of Hope

Presented at: The Sixth Annual Mental Health Services Conference of Australia and New Zealand.
Brisbane, Australia

Presented by: Patricia E. Deegan, Ph.D.

I would like to thank you for this opportunity to speak with you today. It is a special pleasure to be here in your lovely country. I feel the theme of our conference is very important and in many ways reflects the main message in all of my writings. That theme is, "There is a person in here". In many respects, coming to know that there is a person in *here* is the easy part. Remembering to always listen for and to reverence the person over *there* - that can be the more difficult part.

Let me begin by telling you a little about the part of the country I live in. I live in the northeastern part of the United States that we call New England. Where I live, we have four very distinct seasons ranging from the bitter cold of snowy winter, to the muddy season of unfolding colors that we call spring, to the simmering days of summer right through to the spectacular unfolding of autumn when all of the leaves on the trees burst into bright yellows and oranges and reds and then fall to the ground leaving the trees naked and stark and bare. There is always a lesson for me in the cycle of the seasons. I am always reminded that growth happens in a context and that in order for growing things to emerge, environments must change to accommodate that growth.

One spring, after a long and icy winter, I wrote this:

It is springtime and hope is everywhere. It is springtime and it feels like all living things are trembling into being, still wet and new and fragile and determined to put down roots and grow.

I think of a sea rose I watched growing out at a beach near my home this past summer. It is a fragile and tender life, that sea flower. I love to see it. At dawn it moves in a slow upsway as it turns toward the morning star. That sea rose is a light seeker. It bends toward the light. It is a light-seeker whose roots reach way down into the darkness of the earth. In fact, it was in darkness that his new life began.

Way back in January and February, when the icy winds lashed across those dunes and the days were short and the light gave no warmth, even then, way down under the ground, this new life was waiting. Nobody could see it, nobody was there to witness it, and yet this promise of a sea flower waited. It waited in that icy darkness for the sands to begin to thaw. It waited for the rains to come and loosen the earth. And then, ever so slowly, it began to stir. Moving one grain of sand at a time, it began to grow.

It did not grow straight toward the light at first. No. First its growth sought a downward course, reaching, stretching, blindly groping through shifting sands to find a solid place. A place to be rooted. A good soil to cling to and to be nurtured by. A home soil that could sustain it even in driving rains and tormenting winds. And then, having rooted itself in this way, the sea rose began its journey toward the light. Poking through the darkness, that sea flower emerged tiny and lovely and insistent and courageous. On frail and trembling limbs, this small thing rose to a new life…

That sea rose teaches us a lot about hope. It teaches us that hope emerges out of darkness. It teaches us that hope can grow in nurturing environments that allow one to become rooted and secure. And I have come here today to celebrate the hope symbolized by that sea rose.

I believe it is a spirit of hope that gathers us here together today. We come from the far corners of the world : from Australia, New Zealand, the United States, Canada, Sweden, Ireland China and many other countries. We are direct service workers and administrators, policy makers and family members, service users and mental health professionals. Fifteen years ago you would never have caught us all in the same room together! Indeed, ten years ago we would hardly even speak to each other! But here we are, gathered together - social workers sitting next to family members who are sitting next to policy makers, who are sitting next to casemanagers, who are sitting next to academicians who are sitting next to service users . . . What is going on here? Are the old rules being broken? Is the old order shaking a bit at the foundation? IS THERE A CONSPIRACY GOING ON?

I love the word conspiracy. It comes from the Latin "conspirare" which means to breath the spirit together. What is the spirit we are breathing together here today?

It is a spirit of hope. Both individually and collectively we have refused to succumb to the images of despair that so often are associated with mental illness. We are a conspiracy of hope and we are pressing back against the strong tide of oppression which for centuries has been the legacy of those of us who are labeled with mental illness. We are refusing to reduce human beings to illnesses. We recognize that within each one of us there is a person and that, as people, we share a common humanity with those who have been diagnosed with mental illness. We are here to witness that people who have been diagnosed with mental illness are not things, are not objects to be acted upon, are not animals or subhuman life forms. We share in the certainty that people labeled with mental illness are first and above all, human beings. Our lives

But before speaking further of hope and humanity, I want to share with you what it is like to be diagnosed at a young age with mental illness and to lose all hope. I want to tell you about the dark winter of anguish and apathy when we give up hope and just sit and smoke and drink coffee.

For those of us who have been diagnosed with mental illness and who have lived in the sometimes desolate wastelands of mental health programs and institutions, hope is not just a nice sounding euphemism. It is a matter of life and death. We know this because, like the sea rose, we have known a very cold winter in which all hope seemed to be crushed out of us. It started for most of us in the prime of our youth. At first we could not name it. It came like a thief in the night and robbed us of our youth, our dreams, our aspirations and our futures. It came upon us like a terrifying nightmare that we could not awaken from.

And then, at a time when we most needed to be near the one's we loved, we were taken away to far off places. At the age of 14 or 17 or 22 we were told that we had a disease that had no cure. We were told to take medications that made us slur and shake, that robbed our youthful bodies of energy and made us walk stiff like zombies. We were told that if we stayed on these medications for the rest of our lives we could perhaps maintain some semblance of a life. They kept telling us that these medications were good for us and yet we could feel the high dose neuroleptics transforming us into empty vessels. We felt like will-less souls or the walking dead as the numbing indifference and drug induced apathy took hold. At such high dosages, neuroleptics radically diminished our personhood and sense of self.

As these first winds of winter settled upon us we pulled the blankets up tight around our bodies but we did not sleep. During those first few nights in the hospital we lay awake. You see, at night the lights from the houses in the community shine through the windows of the mental institution. Life still went on out there while ours crumbled all about us. Those lights seemed very, very far away. The Zulu people have a word for our phrase "far away". In Zulu "far away" means, "There where someone cries out : 'Oh mother, I am lost" (Buber 1958, p. 18).

And indeed, this is how far away it felt in the mental hospital. The road back home was not clear. And as we lay there in the darkness we were scared and could not even imagine the way out of this awful place. And when no one was looking we wept in all of that loneliness.

But when morning came we raged. We raged against the bleak prophesies that were being made for our lives. They are wrong! They are wrong! We are not crazy. We are not like those other ones over there who have been in this hospital too long. We are different. We will return home and everything will be just the same. It's just a bad dream. A temporary setback.

In time we did leave the hospital. We stood on the steps with our suitcases in hand. We had such courage - our youthful optimism waved like triumphant flags at a homecoming parade. We were going to make it. We were never going to come back to the hospital again.

Some did make it. But most of us returned home and found that nothing was the same anymore. Our friends were frightened of us or were strangely absent. They were overly careful when near us. Our families were distraught and torn by guilt. They had not slept and their eyes were still swollen from the tears they cried. And we, we were exhausted. But we were willing to try. And I swear, with all the courage we could muster we tried to return to work and to school, we tried to pick up the pieces, and we prayed for the strength and perseverance to keep trying. But it seemed that God turned a deaf ear to our prayers. The terrible distress came back and our lives were shattered once again.

And now our winter deepened into a bone chilling cold. Something began to die in us. Something way down deep began to break. Slowly the messages of hopelessness and stigma which so permeated the places we received treatment, began to sink in. We slowly began to believe what was being said about us. It seemed that the system tried to break our spirit and was more intent on gaining, even coercing our compliance, than listening to us and our needs.

We found ourselves undergoing that dehumanizing transformation from being a person to being an illness: "a schizophrenic", "a multiple", "a bi-polar" (Deegan 1992). Our personhood and sense of self continued to atrophy as we were coached by professionals to learn to say, "I -polar"; "I am a multiple". And each time we repeated this dehumanizing litany our sense of being a person was diminished as "the disease" loomed as an all powerful "It", a wholly Other entity, an "in-itself" that we were taught we were powerless over.

Professionals said we were making progress because we learned to equate our very selves with our illness. They said it was progress because we learned to say "I am a schizophrenic". But we felt no progress in this. We felt time was standing still. The self we had been seemed to fade farther and farther away, like a dream that belonged to somebody else. The future seemed bleak and empty and promised nothing but more suffering. And the present became an endless succession of moments marked by the next cigarette and the next.

So much of what we were suffering from was overlooked. The context of our lives were largely ignored. The professionals who worked with us had studied the science of physical objects, not human science. They did not understand what the neurologist Oliver Sacks (1970) so clearly articulates: "To restore the human subject at the center - the suffering, afflicted, fighting, human subject - we must deepen a case history to a narrative or tale; only then do we have a 'who' as well as a 'what', a real person, a patient, in relations to disease - in relations to the physical. . . the study of disease and identity cannot be disjoined. . . (stories) bring us to the very intersection of mechanism and life, to the relation of physiological processes to biography" (p.viii). But no one asked for our stories. Instead they thought our biographies as schizophrenics had been already been written nearly a century before by Kraeplin and Blueler.

Yet much of what we were going through were simply human experiences - experiences such as loss and grief and shock and fear and loneliness. One by one our friends, relatives and perhaps even families left us. One by one the professionals in our lives moved on and it became too difficult to trust anyone. One by one our dreams and hopes were crushed. We seemed to lose everything. We felt abandoned in our ever-deepening winter.

The weeks, the months or the years began to pass us by. Now our aging was no longer marked by the milestones of a year's accomplishments but rather by the numbing pain of successive failures. We tried and failed and tried and failed until it hurt too much to try anymore. Now when we left the hospital it was not a question of ***would*** we come back, but simply a question of ***when*** would we return. In a last, desperate attempt to protect ourselves we gave up. We gave up trying to get well. Giving up was a solution for us. It numbed the pain. We were willing to sacrifice enormous parts of ourselves in order to say "I don't care". Our personhood continued to atrophy through this adaptive strategy of not caring anymore. And so we sat in chairs and smoked and drank coffee and smoked some more.. It was a high price to pay for survival. We just gave up. And winter settled in upon us like a long cold anguish.

I'm sure that many of us here today know people with psychiatric disabilities who are lost in the winter of anguish and apathy I have just described. It is a time of real darkness and despair. Just like the sea rose in January and February, it is a time when nothing seems to be growing except the darkness itself. It is a time of giving up. Giving up is a solution. Giving up numbs the pain because we stop asking "why and how will I go on?". Even the simplest of tasks is overwhelming at this time. One learns to be helpless because that is safer than being completely hopeless.

The winter of anguish and the atrophy of the sense of self that I am describing is a hell not only for the ones living it, but also for the one's who love and care for us: friends, relatives and even professionals. I have described what it feels like on the inside as it is being lived. But friends, relatives and professionals see the anguish and indifference from the outside.

From the outside it appears that the person just isn't trying anymore. Very frequently people who show up at clubhouses and other rehabilitation programs are partially or totally immersed in this despair and anguish. On good days we may show up at program sites but that's about all. We sit on the couch and smoke and drink coffee. A lot of times we don't bother showing up at programs at all. From the outside we may appear to be among the living dead. We appear to be apathetic, listless, lifeless. As professionals, friends and relatives we may think that these people are "full of excuses", they don't seem to try anymore, they appear to be consistently inconsistent, and it appears that the only thing they are motivated toward is apathy. At times these people seem to fly into wishful fantasies about magically turning their lives around. But these seem to us to be only fantasies, a momentary refuge from chronic boredom. When the fantasy collapses like a worn balloon, nothing has changed because no real action has been taken. Apathy returns and the cycle of anguish continues.

Staff, family and friends have very strong reactions to the person lost in the winter of anguish and apathy. From the outside it can be difficult to truly believe that there really is a person over there. Faced with a person who truly seems not to care we may be prompted to ask the question that Oliver Sacks (1970, p. 113) raises: "Do you think William (he) has a soul? Or has he been pithed, scooped-out, de-souled, by disease?" I put this question to each of us here today. Can the person inside become a disease? Can schizophrenia pith or scoop-out the person so that nothing is left but the disease? Each of us must meet the challenge of answering this question for ourselves. In answering this question, the stakes are very high. Our own personhood, our own humanity is on the line in answering this question. Let me explain:

Sitting in the day room, literally couched in a cigarette smoke screen, the profound apathy and indifference we may encounter in another person will challenge our own humanity and our own capacity to be compassionate. We may question whether there really is a person over there. In such an encounter Martin Buber (1958) would instruct us that the I - Thou relationship is challenged. If we relate to a person as if they were a disease then we enter an I - It relationship. The I-It relationship diminishes our own humanity. Of course, the great work that faces us is to hold the sanctity of the person as Thou, even when the person may be lost to themselves. That is the great act of compassion. To hold the personhood of a person even when they may be lost to themselves. This deepens our humanity or, to paraphrase Martin Buber - I become I by saying Thou (p.11).

However, when faced with a person lost in anguish and apathy, there are a number of more common responses than finding a way to establish an I-Thou relationship. A frequent response is what I call the "frenzied savior response". We have all felt like this at one time or another in our work. The frenzied savior response goes like this : The more listless and apathetic the person gets, the more frenetically active we become. The more they withdraw, the more we intrude. The more will-less they become, the more willful we become. The more they give up, the harder we try. The more despairing they become, the more we indulge in shallow optimism. The more treatment plans they abort, the more plans we make for them. Needless to say we soon find ourselves burnt out and exhausted. Then ***our*** anger sets in.

Our anger sets in when our best and finest expectations have been thoroughly thwarted by the person lost in anguish and apathy. We feel used and thoroughly unhelpful. We are angry. Our identities as helping people are truly put to the test by people lost in the winter of anguish and indifference. At this time it is not uncommon for most of us to begin to blame the person with the psychiatric disability at this point. We say things like : "They are lazy. They are hopeless. They are not sick, they are just manipulating. They are chronic. They need to suffer the natural consequences of their actions. They like living this way. They are not mad, they are bad. The problem is not with the help we are offering, the problem is that they can't be helped. They don't want help. They should be thrown out of this program so they can 'hit
Then they will finally wake up and accept the good help we have been offering."

During this period of anger and blaming a most interesting thing happens. We begin to behave just like the person we have been trying so hard to save. Frequently at this point staff simply give up. We enter into our own despair and anguish. Our own personhood begins to atrophy. We too give up. We stop trying. It hurts too much to keep trying to help the person who seems to not want help. It hurts too much to keep trying to help and failing. It hurts too much to keep caring about them when they can't even seem to care about themselves. At this point ***we*** collapse into our own winter of anguish and a coldness settles into our hearts.

We are no better at living in despair than are people with psychiatric disabilities. We cannot tolerate it so we give up too. Some of us give up by simply quitting our jobs. We reason that high tech computers do as they are told and, besides, the pay is better. Others of us decide not to quit, but rather we grow callous and hard of heart. We approach our jobs like the man in the Dunkin Donuts commercial: "It's time to make the donuts, it's time to make the donuts". Still others of us become chronically cynical. We float along at work like pieces of dead wood floating on the sea, watching administrators come and go like the weather; taking secret delight in watching one more mental health initiative go down the tubes; and doing nothing to help change the system in a constructive way. These are all ways of giving up. In all these ways we live out our own despair.

Additionally entire programs, service delivery systems and treatment models can get caught up in this despair and anguish as well. These systems begin to behave just like the person with a psychiatric disability who has given up hope. A system that has given up hope spends more time screening out program participants than inviting them in. Entry criteria become rigid and inflexible. If you read between the lines of the entry criteria to such programs they basically state: If you are having problems come back when they are fixed and we will be glad to help you. Service systems that have given up hope attempt to cope with despair and hopelessness by distancing and isolating the very people they are supposed to be serving. Just listen to the language we use: In such mental health systems we have "gatekeepers" whose job it is to "screen" and "divert" service users. In fact, we actually use the language of war in our work. For instance we talk about sending "front-line staff" into the "field" to develop treatment "strategies" for "target populations".

Is there another alternative? Must we respond to the anguish and apathy of people with psychiatric disability with our own anguish and apathy? I think there is an alternative. The alternative to despair is hope. The alternative to apathy is care. Creating hope filled, care filled environments that nurture and invite growth and recovery is the alternative.

Remember the sea rose? During the cold of winter when all the world was frozen and there was no sign of spring, that seed just waited in the darkness. It just waited. It waited for the soil to thaw. It waited for the rains to come. When the earth was splintered with ice, that sea rose could not begin to grow. ***The environment around the sea rose had to change before that new life could emerge and come into being.***

People with psychiatric disabilities are waiting just like that sea rose waited. We are waiting for our environments to change so that the person within us can emerge and grow.

Those of us who have given up are not to be abandoned as "hopeless cases". The truth is that at some point every single person who has been diagnosed with a mental illness passes through this time of anguish and apathy, even if only for a short while. Remember that giving up is a solution. Giving up is a way of surviving in environments which are desolate, oppressive places and which fail to nurture and support us. The task that faces us is to move from just surviving, to recovering. But in order to do this, the environments in which we are spending our time must change. I use the word environment to include, not just the physical environment, but also the human interactive environment that we call relationship.

From this perspective, rather than seeing us as unmotivated, apathetic, or hopeless cases, we can be understood as people who are waiting. We never know for sure but perhaps, just perhaps, there is a new life within a person just waiting to take root if a secure and nurturing soil is provided. This is the alternative to despair. This is the hopeful stance. Marie Balter expressed this hope when asked, "Do you think that everybody can get better?" she responded: "It's not up to us to decide if they can or can't. Just give everybody the chance to get better and then let them go at their own pace. And we have to be positive - supporting their desire to live better and not always insisting on their productivity as a measure of their success". (Balter 1987, p.153).

So it is not our job to pass judgment on who will and will not recover from mental illness and the spirit breaking effects of poverty, stigma, dehumanization, degradation and learned helplessness. Rather, our job is to participate in a conspiracy of hope. It is our job to form a community of hope which surrounds people with psychiatric disabilities. It is our job to create rehabilitation environments that are charged with opportunities for self-improvement. It is our job to nurture our staff in their special vocations of hope. It is our job to ask people with psychiatric disabilities what it is they want and need in order to grow and then to provide them with good soil in which a new life can secure its roots and grow. And then, finally, it is our job

to wait patiently, to sit with, to watch with wonder, and to witness with reverence the unfolding of another person's life.

That sounds good but how do we do it? I have some very concrete suggestions as to how to enter into a conspiracy of hope and build communities of hope around people who have lost hope.

First we must be committed to changing the environments that people are being asked to grow in. We must recognize that real change can be quite uncomfortable and sometimes I worry we will content ourselves with superficial change. I worry about new and catchy words like consumer integration, empowerment, clubhouse models and partnership. It seems to me that over the decades we keep coming up with all kinds of trendy words and names to call each other. For instance in the fifties it was the doctors and the patients. In the sixties it was the staff and the clients. In the seventies it was the providers and the consumers. In the eighties it was the staff and the members. Now in the nineties we have "shareholders" and the Managed Care Corporations.

Yes, the names we call each other have certainly changed. But I would argue that the fundamental relationship between those labeled with mental illness and those who are not, has remained essentially unchanged. There is a wise old monk who lives in the Nova Nada community, out in Kemptville, Nova Scotia. His name is Fr. William MacNamara. When talking about our attempts to bring about change, he says: "It's like we keep rearranging the chairs on the deck of the Titanic but all we really achieve through this effort is a better view while going down". That's the big danger of simply using the newest program designs and politically correct language. If we're not careful, all this will amount to is rearranging the chairs on the deck of a sinking ship. Somebody has got to say, "Stop! Wait! Forget the catchy boat we call the mental health system and we are all going down with it!"

You see, I would argue that until the fundamental relationship between people who have been psychiatrically labeled and those who have not changes, until the radical power imbalance between us is at least equalized, until our relationships are marked by true mutuality, until we stop using barbaric practices such as restraint and seclusion while trying to convince people that such torture is for there own good, and until we recognize the common ground of our shared humanity and stop the spirit breaking effects of dehumanization in the mental health system, then that gaping hole will continue to sink the best of our efforts.

The human-interactive environment of mental health programs and the community must change if people are going to move from just surviving to the journey of recovery. We must stop exercising "power over" the people we work with. This only produces unnecessary dependency and learned helplessness. Instead we must join with people like Dr. Jean Baker Miller (1976) and other scholars at the Stone Center at Wellesley College. Following their lead we must begin to think in terms of having "power with" or "creating power together" rather than

having "power and control over" the people we work with. In this way traditional power relationships, which have historically been so oppressive for people with psychiatric disabilities, will change. Specifically, this means we must stop using the phrase, "I judge this to be in the client's best interest" and instead ask people what they want for their own lives and provide them with the skills and support to achieve it.

We must commit ourselves to removing environmental barriers which block people's efforts towards recovery and which keep us locked in a mode of just trying to survive. For instance, I would suggest examining the following questions:

1. Are the people we work with overmedicated? Very often the apathy, lack of motivation, and indifference we observe is an effect of neuroleptics. Are we teaching consumer/survivors about this drug effect and helping them effectively advocate for medication changes and/or reductions? The multinational drug industry is literally making a fortune through the sales of these drugs. Our priority is not to increase their quarterly profit margins. Our priority is to support people in their recovery process. It is not possible to actively participate in our own recovery process when we are in state of drug induced mental Parkinsonism, apathy and indifference.

2. Are consumer/survivors in both community based and hospital programs involved in evaluating staff work performance? Who better knows how effective a staff person is than those receiving services from that staff person? Additionally, are we providing consumer survivors with the skills training and support to conduct such evaluations?

3. Are program participants and hospital inpatients receiving peer skills training on how to participate in and effectively get what they want from a treatment team? Are we allowed to sit through the entire treatment--planning meeting and are staff committed to speaking in plain English so we can understand the conversation? Are there peer advocates who are available to come to the treatment planning meetings with us? Are there opportunities to meet prior to the team meeting in order to strategize what we want to get out of the meeting and how to go about presenting our ideas? Is there time to role-play speaking up and dealing with questions prior to the treatment-planning meeting?

4. Are there separate toilets or eating space for staff and program participants? If there are, they should be eliminated. This is called segregation and creates second-class citizens.

5. Who can use the phones? Who makes what decisions? Who has the real power in this program? Information is power and having access to information is empowering. What are the barriers to getting information in the program?

6. Do we understand that people with psychiatric disabilities possess valuable knowledge and expertise as a result of their experience? Do we nurture this important human resource? Are peer run, mutual help groups available? Are we actively seeking to hire people with psychiatric disabilities and to provide the supports and accommodation they may request?

These are just some suggestions about how to create environments in which it is possible for people to grow.

Then, as we build these hope filled environments, we must recognize that people with psychiatric disabilities do not "get rehabilitated" in the same sense that cars "get tuned up" (Deegan 1988). We are not passive objects which professionals are responsible for "rehabilitating". Many of us find this connotation of the word rehabilitation to be oppressive. We are not objects to be acted on. Rather we are fully human subjects who can act, and in acting can change our situation.

We are not objects to be fixed. Such a connotation robs us of our own sense of autonomy and self-determination. It places responsibility in the wrong place. It perpetuates the myth that we are not and cannot be responsible for our own lives, decisions and choices.

The truth is that nobody has the power to rehabilitate anybody else's life. This is clearly evidenced in the fact that we can make the finest and most advanced rehabilitation technologies and programs available to people with disabilities and still fail to help them. As it is said, "You can lead a horse to water but you can't make it drink". Something more than just good services is needed. That "something more" is what I call recovery.

The concept of recovery differs from that of rehabilitation in as much as it emphasizes that people are responsible for their own lives and that we can take a stand toward our disability and what is distressing to us. We need not be passive victims. We need not be "afflicted". We can become responsible agents in our own recovery process. That is why it is so dangerous to reduce a person to being an illness. If we insist that a person learn to say, "I am a schizophrenic", then in essence we are insisting that the person equate their personhood with illness. Through such a dehumanizing reduction the disease takes on what is called a "master status" in terms of identity. Thus when a person learns to believe "I am a schizophrenic", when their identity is synonymous with a disease, then there is no one left inside to take on the enormous work of recovery. That is why we must always help people to use person first language i.e., I am a person labeled with schizophrenia; I am a person diagnosed with mental illness, etc. Person first language always reminds us that first and foremost we are human beings who can take a stand toward what is distressing to us.

Each person's journey of recovery is unique. Indeed, each of us must discover for ourselves what promotes our recovery and what does not. Some of us find that intermittent or ongoing treatment is an important part of our recovery process. However others find that they no longer require mental health services and leave the system entirely (Ogawa, 1987)

For some of us who have historically used or abused drugs of alcohol, or who have grown up in alcoholic families, or who have survived childhood sexual, emotional and/or physical abuse, participation in various self help and twelve step programs may play a vital role in our recovery process.

Many of us find that social and vocational rehabilitation programs offer us unique opportunities and we use these services as part of our recovery process. Most of us find that developing friendships based on love and mutual respect is very important to our recovery. Of course, permanent, affordable and fully integrated housing is fundamental to the recovery process. Many of us find that participating in a spiritual community of our choice gives us the strength and hope to keep working hard in our recovery process.

Finally, many of us find it important to participate in consumer/survivor run support networks and advocacy groups in an effort to help change the mental health system, to establish

alternatives to traditional services, to make government aware of our needs, to fight for our full civil rights and to collectively struggle for social justice. In fact, I use the term recovery to refer not only to the process of recovering from mental illness, but also to refer to recovering from the effects of poverty, second class citizenship, internalized stigma, abuse and trauma sustained at the hands of some "helping professionals", and the spirit breaking effects of the mental health system. Indeed, self help and social action cannot be arbitrarily separated. At some point helping ourselves includes joining together as a group to fight the injustices that devalue us and keep us in the position of second class citizens.

Recovery does not refer to an end product or result. It does not mean that one is "cured" nor does not mean that one is simply stabilized or maintained in the community. Recovery often involves a transformation of the self wherein one both accepts ones limitation and discovers a new world of possibility. This is the paradox of recovery i.e., that in accepting what we cannot do or be, we begin to discover who we can be and what we can do. Thus, recovery is a process. It is a way of life. It is an attitude and a way of approaching the day's challenges. It is not a perfectly linear process. Like the sea rose, recovery has its seasons, its time of downward growth into the darkness to secure new roots and then the times of breaking out into the sunlight. But most of all recovery is a slow, deliberate process that occurs by poking through one little grain of sand at a time.

As the sea rose teaches us, the work of growth is slow and difficult but the result is beautiful and wondrous. We have chosen very difficult work. Sometimes I think we are a little weird for choosing this line of work. I mean, computers don't ask that we grow and the pay is certainly better. But we stick with this work and are faithful to it. Why? Because we are part of a conspiracy of hope and we see in the face of each person with a psychiatric disability a life that is just waiting for good soil in which to grow. We are committed to creating that good soil. And so I celebrate you. I celebrate the strong and fiercely tenacious spirit of people with psychiatric disabilities. I celebrate the person within each of us. I celebrate hope. I celebrate our conspiracy. And I think we all deserve a round of applause. Thank you!

References

Balter, M. & Katz, R. (1987). Sing no sad songs: The Marie Balter Story. The Balter Institute, Ipswich MA.

Buber, M. (1958). I and Thou (Trans. By Ronald Gregor Smith). New York: Charles Scribner's Sons.

Deegan, P. (1992). The Independent Living Movement and people with psychiatric disabilities : Taking back control over our own lives. Psychosocial Rehabilitation Journal. 15, 3-19.

Deegan, P. (1990). Spirit breaking: When the helping professions hurt. The Humanistic Psychologist 18 (3), 301-313.

Deegan, P. (1988). Recovery : The lived experience of rehabilitation. Psychosocial Rehabilitation Journal XI (4), 11 - 19.

Miller, J.B. (1976). Toward a new psychology of women, Boston : Beacon Press.

Ogawa, K., Miya, M., Watarai, A., Nakazawa, M., Yuasa, S., & Utena H. (1987). "A long-term follow-up study of schizophrenia in Japan – with special reference to the course of social adjustment. British Journal of Psychiatry, 151, 758-765.

Sacks, O. (1970). The man who mistook his wife for a hat and other clinical tales. New York, Harper & Row

Vanier, J. (1988). The broken body: Journey to wholeness. New York: Paulist Press.